The physiotherapist and occupational therapist as information providers to caregivers of children living in the United Kingdom, with a diagnosis of Cerebral Palsy, during transition from primary to secondary school education

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Award date:
2019

Awarding institution:
Coventry University

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By

Amy Howells

Masters by Research

May 2019

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A thesis submitted in partial fulfilment of the University's requirements for the Degree of Master of Research

Certificate of Ethical Approval

Applicant:

Amy Howells

Project Title:

Physiotherapy and Occupational Therapy Information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.

This is to certify that the above named applicant has completed the Coventry University Ethical Approval process and their project has been confirmed and approved as Medium Risk

Date of approval:

10 May 2018

Project Reference Number:

P61846

Abstract

Background

Family-centred care has been established as best practice towards the management of children with cerebral palsy (Palisano et al 2009). Yet, children with cerebral palsy require additional support throughout their development. It is known that children have increased needs around the time of transition from primary to secondary school (Rice et al. 2011). However, it is not known how children with cerebral palsy receive support around this transition phase. Clinicians can use information to play an integral role in supporting both caregivers and children, frequently looking to clinical guidelines as to how to provide this support (NICE 2017). Currently, it is unknown how these guidelines are used within UK clinical practice, what and how clinicians use information to support caregivers of children with cerebral palsy at the transition to secondary school. Therefore, this study aimed to describe the current PT and OT information needs of caregivers of children, living within the UK with a diagnosis of cerebral palsy, during the transition from primary to secondary education.

Methods

Survey methodology was used comprising of first and second-round data collection. Gatekeepers circulated online questionnaires designed for two defined participant groups; clinicians and caregivers, recruited via theory-based purposive sampling. In both rounds, quantitative and qualitative data was collected with questionnaires open for 6 weeks. Descriptive and inferential statistics were used to analyse quantitative data whilst content analysis was used to review qualitative responses.

Results

Results described what information is currently provided by clinicians to caregivers of cerebral palsy at the point of transition to secondary school alongside how this information was given. Results demonstrated 6 neglected topics of information which neither clinician group had confidence in providing information on at the transition to secondary school. Results explored positives of providing information to caregivers at the transition to secondary school and provided solutions led by clinicians as to how future information provision could be improved.

Conclusion

Recommendations are provided on the following areas: partnership working, training needs, presentation of information, use of clinical guidelines in practice, role of physiotherapists and occupational therapists in transition of children with cerebral palsy from primary to secondary school. Recommendations are provided for ways to overcome structural and organisational barriers including areas for future research.

Acknowledgements

I would like to thank the following people for their help and support over the last two years.

My director of studies, Dr Tanya Rihtman, for keeping me on track and providing invaluable comments and guidance throughout the duration of this research.

The rest of my supervisory team, Dr Simon Igo and Dr Joanne Opie for your support and direction.

My clinical manager, Louise Kelleher, for your continuous support and encouragement from the start of this endeavour.

To my clinical colleagues at the Sunflower centre for your support when times were tough, covering my clinics when I needed to focus on writing and providing me with words of motivation.

To my fellow colleagues on the MRES programme for sticking together and supporting each other through this journey.

To the participants who shared their experiences by completing the online questionnaires.

My friends for proof reading, sending motivational gifts and always being ready with tea and cuddles.

To my family and my husband, for their unfailing love and support and for always believing in me.

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1 Introduction

Cerebral palsy (CP) is one of the most common childhood disabilities, affecting approximately two children in every 1000 live western births (Eunson 2016; Rosenbaum 2003). Although non-progressive, CP is a significant disorder of motor development with a vast array of clinical presentations (Eunson 2016). Disability can range from severe spastic quadriplegia, with all four limbs of the body affected, to relatively mild hemiplegia, with changes found in one side of the body (Eunson 2016). CP is an umbrella term, to capture the complex and varied nature of the condition. Research studies, such as this, must therefore ensure all presentations are included in the study population to make sure no presentation/type of CP is excluded (Weindling et al. 2007).

The complexity of CP is considered in the National Institute of Clinical Excellence (NICE) guidelines (2017, 2012) which were specifically created to assist healthcare professionals in their management of children with CP. Documents such as NICE guidelines have become increasingly important in supporting healthcare professionals in the management of children with complex conditions in the community (Strauss et al. 2007). Not only are children with complex conditions surviving longer, these advances come alongside the introduction of holistic care frameworks such as the International Classification of Functioning, Disability and Health (ICF) (Raina et al. 2005, Strauss et al. 2007, World Health Organisation 2001). Frameworks such as the ICF have been instrumental in changing the approach to managing children with CP, encouraging a shift towards the empowerment of individuals and their families (World Health Organisation 2001). Highlighting the need to concentrate on participation and engagement as opposed to solely the health condition, the ICF has generated changes in healthcare systems, shifting focus from inpatient management towards community care (Raina et al. 2005, World Health Organisation 2001).

More specifically, the ICF has enabled a movement from condition-focused care to child-focused care and more recently to family-centred care (FCC) (Kuo et al. 2012). Classed as best practice within paediatric rehabilitation, FCC focuses on services listening and being responsive to family needs (Kruijsen-Terpstra et al. 2014, Palisano et al. 2009). FCC is frequently used within healthcare research to incorporate wider factors which influence an individual's healthcare management (Almasri et al. 2011). When considering a child with CP, wider factors may include family members desire for

information or the necessary support required for a child to achieve their goals (Almasri et al. 2011).

Due to these developments, activity, exercise and participation of children with CP within their environment are now seen as achievable goals when facilitated by community clinicians such as physiotherapist (PTs) and occupational therapists (OTs). With the holistic nature of FCC, it has become common for families to look to therapists to provide regular advice and information (Weindling et al. 2007). With skills of information dissemination and communication as core standards, therapists have quickly become key resources in bridging the gap between the medical management and management of children with CP within their environments, for example schools (Almasri, An and Palisano 2017, Health and Care Professions Council 2013, Heath and Care Professions Council 2013, Mahon and Cusack 2002, Rice et al. 2015). Ensuring caregivers have the information, understanding and access to services to support their child is vital for the successful management of CP in the community.

During periods of transition, caregivers' information needs have been shown to increase (Bindels-de Heus et al. 2013, Rice et al. 2015). Transition between education environments, specifically movement to secondary school in the UK, often encompasses a move to a new, larger school. Unlike transition into nursery or primary school, this transition is usually coupled with reduced parental contact with the school, a feature encouraged to increase independence as the child reaches adolescence (Rice et al. 2015). This can be a daunting step for many children, especially for children with CP as this may mean change in staff involved in personal care, therapy routines and staff who are attuned to the daily requirements of support which enable to them to access both their educational environment and curriculum.

Despite knowledge of increased stresses during transition to secondary school, how children with CP and their caregivers are supported by professionals at this time remains an under-researched area within the UK. It is currently unknown what support and information is provided by clinicians during transition to secondary school and how this is accepted by caregivers. It is not known if clinical guidelines are effective in supporting clinicians with information provision in clinical practice and whether guideline suggestions are accessible to caregivers. This study aims to gain an insight into the current practices of UK PTs and OTs in their work to support children with CP in the transition to secondary school. Alongside this, this study intends to explore caregivers'

experiences of receiving this information and exploring caregivers' information needs and how PTs and OTs currently meet these.

2 Literature Review

Family-centred care principles are particularly important in the rehabilitation of children with CP, when used to build collaboration between families and professionals during which the family's impact on the child's wellbeing can be understood (Almasri, An and Palisano 2017). FCC principles can be closely related to the work of Bronfenbrenner and the development of his ecological systems model (Bronfenbrenner 1979). In his work, Bronfenbrenner set out to develop a common language for professionals to use when discussing the importance of influencing factors on child development, encouraging research assessing specific experiences within society (Bronfenbrenner 1979). The model considers a multi-layered system through which the individual can influence or be influenced by the elements around them (Bronfenbrenner and Morris 2006). Bronfenbrenner's (1979) model explores the complexity of the contextual factors surrounding the individual at the centre of care, in the case of this study the child with CP. As this study aims to focus on caregivers' perceptions and the existing relationships which form a dialogue around the developing child, Bronfenbrenner's model allows deeper analysis of not only the present contextual factors but the consideration of the influence of these in a multi-layered system. Other models such as the ICF (World Health Organisation 2001) and the model of human occupation (MOHO) (Kielhofner 2008) help to focus on the contextual factors surrounding the child, for example environment, and assist clinicians to apply this to clinical context. However, Bronfenbrenner's model enables a thorough, detailed approach to how each factor is placed within the context of layers and how these may impact the developing child at the centre of care (Bronfenbrenner 1979).

Bronfenbrenner's model acknowledges the importance of the voice of the developing individual within the centre of care, while simultaneously reinforcing the importance and impact of the relationships and interactions surrounding the child, making it a suitable model for exploring the roles of caregivers and clinicians as per the aims of this study. Highlighting the individual at the centre of each ecosystem as an 'active, growing human being' Bronfenbrenner calls for professionals to consider the properties of the immediate setting, defined as the microsystem, in which the individual lives (Bronfenbrenner 1979). Using the model to outline the microsystem for a child with CP pushes professionals to further consider how the child may be affected by the relations between these settings (mesosystem and exosystem) and finally by the context in which the settings are embedded (macrosystem) (Bronfenbrenner 1979). Bronfenbrenner likens the model to

a Russian doll with independent yet parallel systems, getting larger in size with each system (Bronfenbrenner 1979). Considering Bronfenbrenner's approach alongside relevant literature in the context of this study, it is possible to contextualise the model for a child with CP, as seen in figure 1. Embedding the concepts of the model will provide a framework for discussion of the approach and the findings of this study.

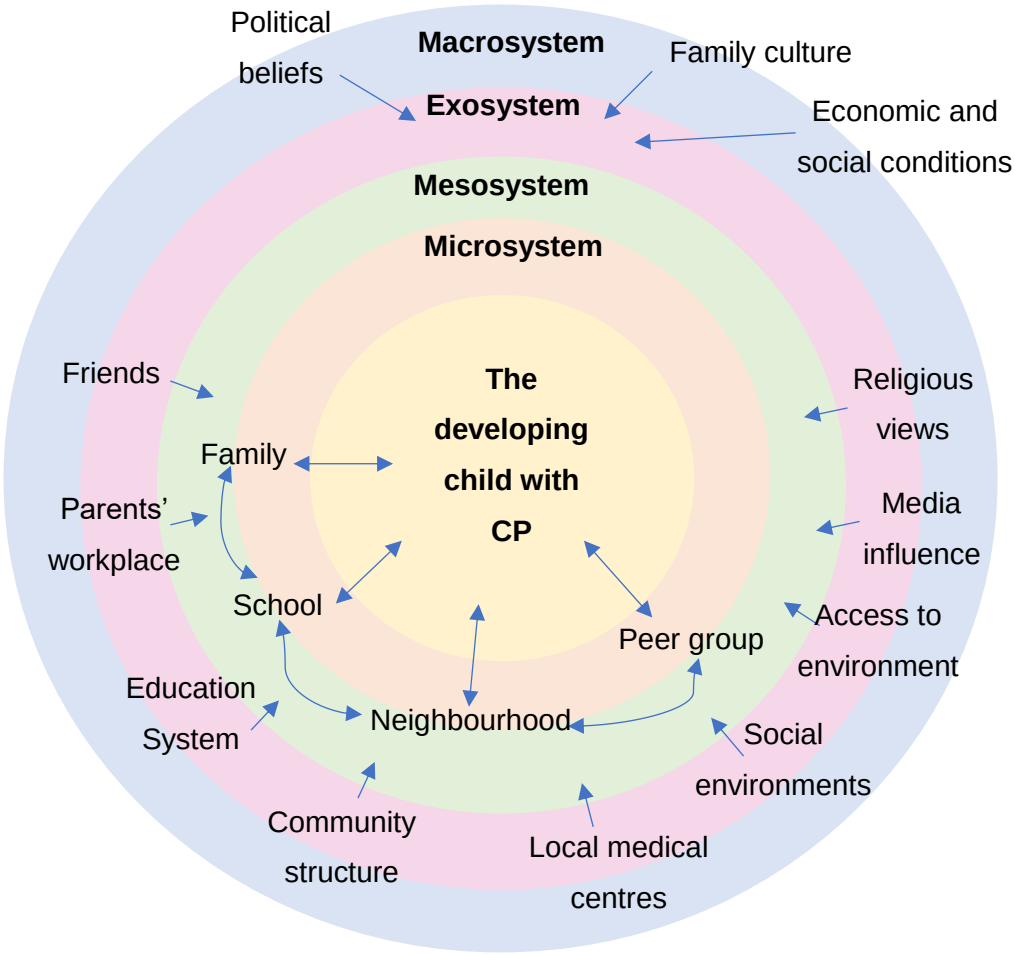


Figure 1 - Example of an ecosystem for a child with CP

As demonstrated within the above model, it is important to consider the voice of the child at the centre, using current literature concerning their experiences to guide the development of research projects and such as within this study the exploration of contextual factors. In a 2013 study by Cheong and Johnston, and a further 2015 study by Cheong, Lang and Johnston, emphasis is given to the importance of self-concept (an individual's perception of self) and the impact this can have on overall wellbeing, social functioning and independence. Cheong and Johnston (2013) highlight the importance of clinicians supporting self-concept in order to improve the quality of life for children with CP. Further supporting this, Bantjes et al (2015) documented the aspiration of children

with CP to achieve independence and autonomy within their social environment, showing their awareness of how their environment could either enable or disable them. It is therefore through considering the outlined environmental factors in Bronfenbrenner's model (1979) that the role and impact that both caregivers and clinicians have on children with CP at the point of transition to secondary school can be described.

It is apparent throughout literature exploring the views of children with CP that youth become aware of their physical limitations as they develop into adolescents, yet preferred to see themselves as being 'challenged' rather than being 'disabled' as this was associated with being taken care of, being infantised or powerless (Brunton and Bartlett 2013, Bantjes et al 2015). Highlighting key issues within their lives, children with CP outline social relationships, home and school environment, self and body and activities and resources as the most important to them (Young et al 2009). Further to this, they consider relationships with wider family members, home life and neighbourhood to be important to their quality of life and value opportunities where they can actively participate in activities to overcome impairment or environmental related challenges (Shikako-Thomas et al 2009, Young et al 2009, Kramer and Hammel 2011). Placing this collective voice of experiences and perceptions at the centre of Bronfenbrenner's model demonstrates the importance of focusing on the wider factors associated with the management of children with CP. It is therefore suitable, due to the aims of this study, that it is guided by the model to consider the interactions and relationships within each of the described layers, focusing on the influence of caregivers and clinicians.

Bronfenbrenner (1979) discusses the importance of activities, defining 'molar activities' to have three characteristics: ongoing, holding momentum of their own and perceived to have meaning/intent. Clinicians, PTs and OTs use activities as an integral part of working with children with CP, using them to guide assessment, progression and where possible treatments (Bobath 1991). Playing a key role in developmental status, activities have the potential to cause change and may provide a measure of a child's maturity. It is however, key to note that the changing nature of each element of the ecosystem is relative to the environment and is required to be assessed on an individual basis (Bronfenbrenner 1979).

Closely linking to FCC principles, using developmental status to guide the management of children with CP may establish how well a child has adapted to their environment. The more complex and varied activities observed within the ecosystem, the more developed

the child will be. However in contrast, therapists may often be required to consider how environments with fewer engagements may have a detrimental effect on development (Bronfenbrenner 1979, Shelton 2018). Although considered the exosystem, it is important for clinicians (PTs and OTs) to consider how they work throughout these systems and their role within creating a developmentally facilitating environment (Bronfenbrenner 1979, Shelton 2018).

Children with CP emphasise the importance of participation and social inclusion within their environment, highlighting the frustration and isolation that can occur with loss of independence or inability to partake in activities (Castle, Imms and Howie 2007, Lindsay 2015, Cussen, Howie and Imms 2012). Alongside this, children with CP acknowledge the benefit and importance of having a supportive family environment, highlighting how their relationships can have a direct impact on their quality of life, hopes and aspirations, yet acknowledge how families can sometimes act as barriers to their participation (Cussen, Howie and Imms 2012, Lindsay 2015). Within the ecosystem Bronfenbrenner explores the notion of transactions, the relationships between two individuals, and roles, a set of activities and relations expected of a person in society. Both transactions and roles present within the child's ecosystem can directly impact their development however the system itself may be changed due to the relationships present (Bronfenbrenner 1979). For example, the people within a child's ecosystem may respond differently to a diagnosis of CP and potential altered development and therefore change their role in the system accordingly.

With the use of FCC principles, the role of parents as primary caregivers for children with CP has been integral to the development of needs-based services (Buran et al. 2009). This approach has demonstrated the potential to enable families to advocate for their child, improve co-ordination in services and improve knowledge acquisition (Almasri et al. 2011, Law et al. 2003). Research into the role of caregivers of children with CP demonstrated the detrimental effect parental stress can have on a child's wellbeing (Raina et al. 2005). Parental stress exists as a temperamental balance between external demands and perceived parental ability to navigate services (Kruijsen-Terpstra et al. 2014, Palisano et al. 2009). Changes in levels of parental stress can be attributed to changes in perceived levels of family functioning, particularly when external demands limit or obstruct family or life objectives (Raina et al. 2005). Due to this, practice and policy reports that parents should be empowered to express their information and service needs (NICE 2017, Siebes et al. 2012).

Research shows that parents are influenced by not only their beliefs about FCC and their child's diagnosis of CP but by the context in which they receive health services (Almasri, An and Palisano 2017, Law et al. 2003). In community management of children with CP, each child's mapping will be unique making it important that PTs and OTs closely consider their role within each child's ecosystem and how their services meet the needs of the individual (Buran et al. 2009, Kruijsen-Terpestra et al. 2016). Roles are important in shaping both relationships and settings (Bronfenbrenner 1979, Shelton 2018). It is the role of individuals within the child's ecosystem to create environments, relationship or activities that support and enhance the child's understanding of the world and their ability to function within it. An ecosystem can be considered developmentally facilitating when it generates settings which present increasingly complex activities, encourage relationships that support development and facilitate roles which help the child to learn more about their ecosystem whilst gathering skills to be effective within it (Bronfenbrenner 1979, Shelton 2018).

Clinical services try to achieve developmentally facilitating settings for management of developing children with CP through embedding FCC principles. Integrating key concepts such as information sharing with families and developing services based on family-identified needs is key to creating a developmentally facilitating environment and has been shown to enhance parental empowerment, self-efficacy and in-turn reduce family functioning needs such as financial and community resourcing (Almasri, An and Palisano 2017, King and Chiarello 2014). Despite this, literature considering information sharing as a key principle in FCC, demonstrates that healthcare providers frequently hold power over how and when information is shared with families, undermining the whole approach (Bronfenbrenner 1979, Siebes et al. 2012).

Previous work by Darrah et al. (2012) expressed the frustration of families of children with CP who felt their opinions where not sufficiently considered and who highlighted difficulties in gaining full information about their child's healthcare needs. This is particularly pertinent for families of children with CP due to the changing nature of associated co-morbidities. Darrah et al.'s (2012) work supports the importance of engaging families in ongoing conversations, as their needs may be broad and affected by specific stages of their child's life or at different transition stages (Almasri, An and Palisano 2017, Palisano et al. 2009).

The development of effective settings within each child's ecosystem is important as it is through these that concepts of adaption and transition can be considered (Shelton 2018).

On first engagement with a setting, the child is still trying to learn the expected activities, relations and roles. As discussed by Bronfenbrenner (1979) and demonstrated in education-based research by Rice et al. (2015), children often move through transition periods with a degree of apprehension towards the formal processes which can take effort and may cause a level of anxiety. Rice et al (2015) reports that strategies delivered by education staff can decrease anxiety over time, supporting Bronfenbrenner's (1979) views that this often occurs as understanding of the setting becomes clearer to the point which they are able to engage and explore the roles available within the setting.

Despite the positives of strategies, Rice et al. (2015) highlights that children often require increased caregiver support when entering new settings such as moving from primary to secondary school. Bronfenbrenner discusses these stages as ecological transitions, defining them as a period where a *'person's position in the ecological environment is altered as a result of a change in role, setting or both'* (Bronfenbrenner 1979:26). In a 2011 study, caregivers who had raised children with CP identified that transition periods require increased co-ordination and additional pre-planning due to their child's condition (Reid et al. 2011). As discussed by Shelton (2018) the approach of Bronfenbrenner (1979), defines transitions and associated characteristics of transition, such as increased stress, effort and learning, as important parts of development. Shelton (2018) discusses how ecological transitions affect not only the ecosystem and setting but also the place of the individual within it. This view is supported by Rice et al. (2015) who demonstrated the ability of transition periods to greatly influence a child's attainment and long-term wellbeing. Bronfenbrenners' work suggests that ecological transitions are a positive development milestone which provide a test of the development which has taken place in previous settings and may also provide an assessment of the child's current development status (Bronfenbrenner 1979).

As mentioned, children experience several transition periods during their development to adulthood, with transition into educational settings occurring at key stages of their development. Transition periods call for a change in responsibility from the parent/caregiver to another individual for example to a nursery practitioner or class teacher. In contrast, transition to secondary school gives way to a gradual shift of responsibility from the caregiver to the child in an attempt to prepare them for adolescence (Rice et al. 2015). Echoing Bronfenbrenner's (1979) views that ecological transitions may provide a test of previous development, Rice et al. (2015), define the first year of secondary school as a window of opportunity to deliver strategies to increase

compliance and wellbeing through empowering all children transitioning. This is supported by the work of Gottfredson and Hussong (2011) who discuss the benefit of interventions around the period of transition due to the potential for long-lasting positive effects. It is essential to consider the above in the context of children with CP. For children with CP parental engagement in the management of their long-term health condition is essential (Kruijsen-Terpstra et al. 2016). Coupled with the diverse nature of the condition and the associated co-morbidities, such as behavioural and communication issues, the provision of individualised and needs-based services can be challenging (Almasri, An and Palisano 2017, Rosenbaum, P. 2011).

Ecological transitions may not go smoothly for children with CP (Bronfenbrenner 1979, Rice et al. 2015). Rice et al. (2015) demonstrated that for children with additional needs the use of generic information and interventions often increased anxiety rather than reducing it. The risks of this, as outlined by Bronfenbrenner (1979) when considering how individuals transition into new settings, are that for children who are unable to adapt, understand or access their new setting, their transition will remain stressful having the potential to negatively affect the child's behaviour. This may even culminate in the child 'adapting' through disengagement or possible avoidance of the setting. It is therefore necessary to recognise the needs of children with CP within the education ecological transition between two settings, in this case from primary to secondary school and the existing roles within the child's mesosystem. Considering roles, activities and relationships in old and new settings, Bronfenbrenner (1979) considers three indirect links that can be present and useful to achieving successful ecological transitions: 1) people 2) communication 3) knowledge. Each setting should be considered to have its own microsystem however it is key to evaluate how the presence of these indirect links can have impact on the success of a child's transition.

Within the education setting, special educational needs co-ordinators (SENCOs) exist as an indirect link facilitating transition and the child's inclusion into the new environment (DOH, DOE 2015). It is a government requirement that each school has a designated SENCO, a qualified teacher either possessing or working towards a national postgraduate award in Special educational needs co-ordination (DOH/DOE 2015). It is the role of the SENCO to co-ordinate child specific provision, including the generation of education and health care plans (EHCPs) whilst liaising closely with all agencies involved in the child's mesosystem. The SENCO should have an up to date knowledge of the local offer and provide support to educational colleagues around special educational needs

(SEN) to ensure children and their families are able to access their education setting. Despite this established role, it is important to note the educational bias to this provision with SENCOs holding no healthcare specific training. It is therefore necessary to recognise the important role and specific role that therapists play in supporting children with SEN, be that through direct work, or through communication and the provision of information to education staff to support inclusion and access (DOH/DOE 2015, Dickinson et al. 2007). Bronfenbrenner defines inter-setting communication as the process where messages are provided from one setting to another with the intent of providing specific information (Bronfenbrenner 1979, Shelton 2018).

This concept is explored by Gulmans et al. (2009) who discuss the relationship between caregivers and education environments, defining their role as 'messengers of knowledge'. Although deemed a positive role for caregivers to adopt, as they can contextualise the information for their child, caregivers often experienced inadequate information sharing from healthcare professionals leading to reduced co-operation and patient-centred care (Gulmans et al. 2009). This work highlights the need for healthcare professionals to provide information to enable parents to support and advocate for their children (Gulmans et al. 2009. Reid et al. 2011). Elaborating on this, Palisano et al. (2009) identifies healthcare professionals as key individuals to offer support and assistance to families during transition. Research documents the requirement for continuing communication during the integration of children into education environments, encouraging healthcare professionals to consider their influence within all areas of the child's life and utilise FCC principles (Almasri, An and Palisano 2017, Mahon and Cusack 2002). However, Palisano et al. (2009) comments on lack of current research into the family needs during the transition from one educational setting to another.

Alongside inter-setting communication, Bronfenbrenner (1979) describes inter-setting knowledge as information or experience that exists in one setting about another setting. Lagoskys, Bartlett and Shaw's (2016) study demonstrated the importance of monitoring the knowledge use of families of children with CP and capturing how families use provided knowledge for involving the entire family in knowledge translation (the process of using information provided) (Lagosky, Bartlett and Shaw 2016). Lagosky, Bartlett and Shaw (2016) emphasise how caregivers use information provided by healthcare professionals to guide their decisions about their child's educational needs. Clinician support in this instance can be instrumental in promoting caregiver self-efficacy in providing support for their child. As suggested by Darrah et al. (2012) and Miller, Colligan

and Colver (2003) families of children with CP, look to medical and educational systems for information, support and assistance however want better information sharing, more frequent communication and wish to work as equals with healthcare professionals (Mahon and Cusack 2002).

Furthermore, Bamm and Rosenbaum (2008) discuss the frequent mismatches in priorities between caregivers and healthcare professionals, stating that caregivers prioritise communication and access to generic information and resources, whereas professional's priorities lay with providing information focused on health conditions. In conjunction with Bamm and Rosenbaum (2008), Palisano et al. (2009) express the changing needs of caregivers over time, discussing the need for common information resources to support families and alleviate the mismatch in priorities. Although based in the United States of America, Palisano et al. build on this work further in their 2011 and 2017 studies. In 2011, they reported that 50% of caregivers expressed needs for more general information about services their child with CP might need and specifically planning for future wellbeing and, in 2017 encouraged clinicians to focus on the importance of providing families with the opportunity for communication and how general information could be used to meet their needs (Almasri et al. 2011, Almasri, An and Palisano 2017)

The changing nature of caregiver's information needs about their child's condition has been documented (Bamm and Rosenbaum 2008, Hummelinck and Pollock 2006, Lagosky, Bartlett and Shaw 2016, Reid et al. 2011). Hummelinck and Pollock (2006) explored caregiver views that healthcare professionals are at fault for not appropriately adapting to the changing needs of the child and family. Caregivers clearly state that their information seeking habits frequently change in line with their immediate concerns about their child (Lagosky, Bartlett and Shaw 2016). Furthermore, caregivers expressed the need for more opportunities to ask questions and learn more about their child's condition stating this would have the greatest benefit as their child matures (Reid et al. 2011). From this research, it is clear caregivers want access to information as their child matures, however it is important to consider what, how and when this information is provided to ensure it meets caregiver needs.

Although focusing on transition of children with CP to adult services, Buran et al. (2009) displays the frequent caregiver concern of overwhelming amounts of information, reporting that information given in bulk can be confusing for caregivers and retrieval of information pertinent to their child can then be difficult. In conjunction with this,

experience of disorganisation of information was a key issue for caregivers within transition periods (Siddiqua and Janus 2017). This issue is discussed within the work of Kruijsen-Terpstra et al. (2016) who demonstrate the challenge on services to provide timely and appropriate generic information to caregivers of children with CP, however suggest improvements in providing this information could have a possible impact on caregiver empowerment. Lagosky, Bartlett and Shaw (2016) suggest that caregivers frequently gauge the quality of information by the source and seek guidance when seeking health information.

Jeglinsky, Autti-Rm and Brogran Carlberg (2012) highlight the views of both caregivers and healthcare professionals working with children with CP regarding lack of written information for families particularly about the condition, therapies and progress. They reported a view echoed throughout the literature, of a lack of information provided about available community services and access to activities (Almasri, An and Palisano 2017, Buran et al. 2009, Jeglinsky, Autti-Rm and Brogren Carlberg 2012, King and Chiarello 2014, Kruijsen-Terpstra et al. 2014, Palisano et al. 2009) However, findings by Knis-Matthews et al. (2011) suggest a more personal mentoring approach in providing resources for caregivers at different stages in their child's development, focusing on needs at a point in time and suggest this approach may benefit the effectiveness of healthcare systems. Kruiksen-Terpestra et al. (2014) support the mentoring approach, discussing the value that caregivers place on having time for personal communication with their healthcare professional, categorising it as one of the highest priorities for achieving successful relationships. This in turn demonstrates the role of healthcare professionals in tailoring research-based information to families which may impact on parental confidence and knowledge of how to manage and empower their child with CP (Lagosky, Bartlett and Shaw 2016).

As demonstrated above, relationships existing within the child's ecosystem can work together or in this case can conflict and potentially cause frustration. Therefore, it is important to consider how the concepts of inter-setting communication and inter-setting knowledge influence the success of a child's transition to secondary school. When discussing Bronfenbrenner's (1979) work, Shelton (2018) states the importance in creating relationships between settings, highlighting the need for the content and type of inter-setting communication and inter-setting knowledge to be considered. This links closely with the style and the content of information shared and how this can cause the above described influence in attitudes towards settings, for example a change in

caregiver attitude due to information provided by healthcare professional (Shelton 2018, Lagoksy, Bartlett and Shaw 2016).

Current NICE guidelines (2017) further support healthcare professionals as information providers to achieve personalised and FCC, whilst considering the role of healthcare professionals in inter-setting communication and knowledge. These guidelines build upon caregiver perceptions of the importance and value of information, providing strategies towards increasing parental self-efficacy and feelings of control (Mitchell and Sloper 2002). Despite the above literature and suggested importance of these concepts it is currently unknown how these guidelines translate into UK clinical practice and how UK clinicians use guidelines to inform how and what information they provide to caregivers of children with CP (Bronfenbrenner 1979). As previously discussed resources implemented at the time of transition to secondary school can have positive long-term impacts on wellbeing and confidence however individual approaches should be considered for children with additional needs and long-term conditions like CP (Rice et al 2015, Gottfedson and Hussong 2009). Therefore, research is required into the current use of information by clinicians at transition to secondary school to understand whether this is successful in supporting caregivers of children with CP as they transition to secondary school.

When considering the importance of information and support for children with CP, NICE guidelines (2017) highlight the need for transparent, accessible information and outline key areas for focus for information provision, presented in Figure 2 below.

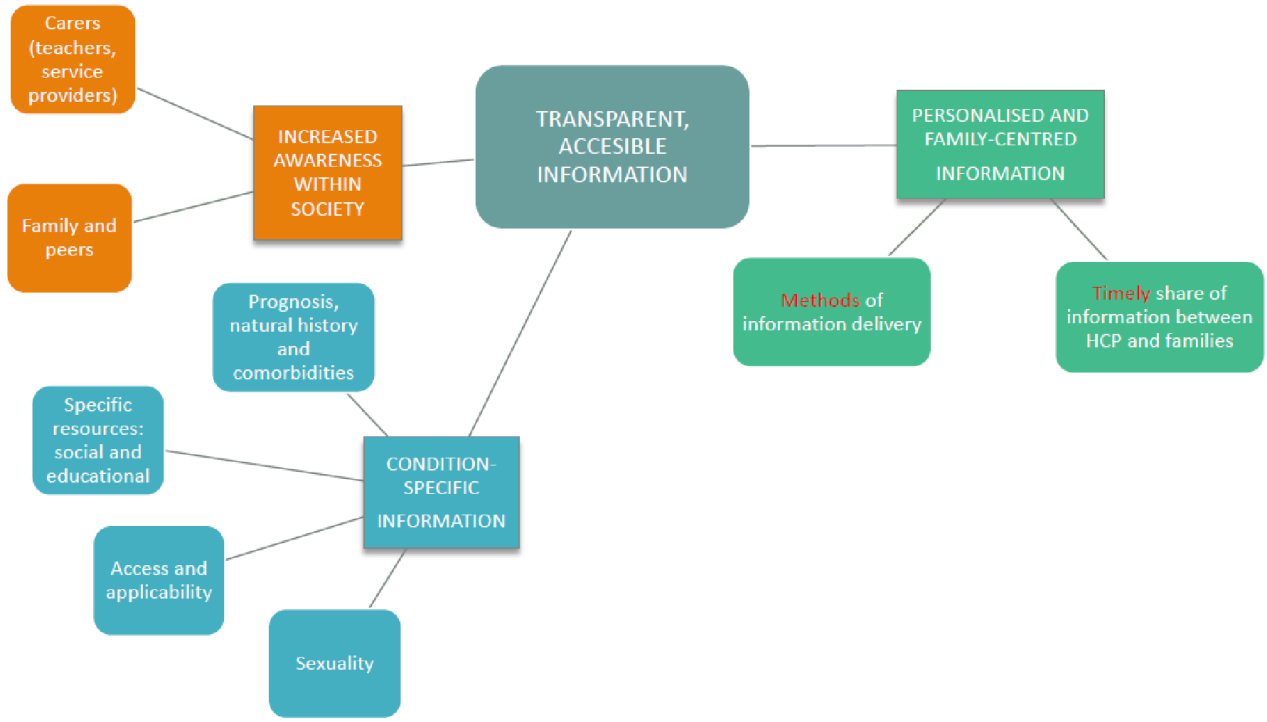


Figure 2 - Theme map of evidence (NICE 2017)

Through analysis of the above areas, guidelines provide the recommendations as to how healthcare professionals can meet caregivers needs (Appendix 1). When considering guideline recommendations in the context of the ecological transition from primary to secondary school, there is a clear focus on FCC principles in the first recommendation also echoing the view of the ICF guiding clinicians to focus on functional abilities and not only impairments (World Health Organisation 2001).

In the seventh and eighth recommendations clinicians are encouraged to consider their role in crossing the boundaries of the child's microsystem, mesosystem and exosystem and how information provision such as inter-setting communication and inter-setting knowledge can influence the child's involvement within their individual system (Bronfenbrenner 1979, NICE 2017). Focusing on Bronfenbrenner's concept of transition, the transition may highlight the child's developmental status in the context of their

ecosystem (Bronfenbrenner 1979). However, it is currently unknown whether this is a good foundation to base successful transition in the UK for children with CP moving to secondary school. It is currently unknown how well families of children with CP are supported by PTs and OTs or how information is used by clinicians in their role to prepare children or caregivers for transition.

Guidelines suggest the use of a 'patient folder' as an information resource to support the child within their environment including through transition (NICE 2017). Patient folders are described as a document in preferred format (either electronic or paper-based) containing relevant information that can be shared with individuals such as extended family, friends or used in health, social care, education and transition settings (NICE 2017). They suggest that this resource can be used within each layer of the child's system and have influence on factors such as education, healthcare and extended family (NICE 2017). However, despite these recommendations there is no current evidence as to how these recommendations are supported in UK clinical practice. It is unknown if caregivers seek out information or have unmet information needs at this period of transition. It is unknown if the areas suggested within the guidelines are acknowledged by clinicians or whether recommendations are accepted by caregivers of children with CP in the UK. Therefore, this study intended to explore the current information needs of caregivers of children with CP, living within the UK. Alongside this, the study intended to describe the current approach of PTs and OTs in the provision of information to caregivers and will use guideline recommendations as a foundation to review current clinical practice.

2.1 Study aims and objectives

Research Question:

What are the current physiotherapy and occupational therapy information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary education?

Study Aim:

To describe the current physiotherapy and occupational therapy information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition to secondary school.

Study Objectives:

- Describe what information is currently provided by PTs and OTs to caregivers of children with CP as they transition to UK secondary school.

- Describe how information is currently provided by PTs and OTs to caregivers of children with CP as they transition to UK secondary school.

- Capture and describe caregivers' experiences of good practice when receiving information from PTs and OTs regarding transition to UK secondary school for children with CP.

- Capture and describe gaps in the nature and means of information provision provided by PTs and OTs to caregivers of children with CP as they transition to UK secondary school.

- Identify caregiver-informed strategies for future information provision from PTs and OTs to caregivers of children with cerebral palsy as they transition to UK secondary school.

3 Methodology and Methods

Considering the researchers' dual role as a clinician, study design and planning focused on an approach with the greatest influence and transferability to clinical practice. Empirical in nature, the study intended to gather caregivers' experiences and their current PT and OT information needs, as their child with CP transitioned to secondary school. The study intended to build on current knowledge and was designed to collect information from two defined populations, caregivers and clinicians. As the study question and objectives were descriptive in nature it was appropriate to collect quantitative and qualitative data (Sim and Wright 2000). Quantitative data was used to provide context, whilst qualitative data was used to give depth and perspective to quantitative findings (Bryman 2016).

Using current literature and NICE guidelines (2017) as a foundation to judge current clinical practice, it was possible to outline study variables and data required to answer the research question. Survey methodology was deemed appropriate to gather information about the population of interest (Sim and Wright 2000). With the study intentions to quantify variables such as what and how information is provided to caregivers of children with CP during the transition to secondary school, an online questionnaire was chosen as an appropriate tool to gather current practices and experiences (Sim and Wright 2000). It was agreed that individual responses would be aggregated to provide a general view of the participants in the context of this study (Sim and Wright, 2000). As is usual with descriptive methodologies the study procedure and data collection instrument were structured and formalised prior to data collection (Sim and Wright 2000:69).

3.1 Participants

Participants were defined into two distinct target populations, caregivers of children with CP transiting to UK secondary school and UK clinicians (PTs and OTs) working with the above children. As the study's intention was to gather views and experiences of both populations, a theory-based purposive sampling approach was used to target recruitment to those with relevant experiences (Patton 2002). As the study intended to describe the current information needs throughout the UK, a survey approach meant it was possible to access a nation-wide sample within the limits of the available resources (Bryman 2016). This approach meant the data collection instrument was able to be shared throughout the UK, meaning distance from the researcher's location did not

preclude participation. Participants from both populations were reviewed against pre-determined inclusion and exclusion criteria, outlined in Table 1.

Table 1 - Participant inclusion and exclusion criteria

Participant group	**Inclusion Criteria**	**Exclusion Criteria**
Caregivers	• Caregiver of a child with a diagnosis of Cerebral Palsy. • Child who transitioned from primary to secondary school (sept 2018 or 2017-2018). • Living in the UK • Child received physiotherapy and/or occupational therapy treatment.	• Diagnosis other than Cerebral palsy, including chronic illnesses (e.g. cancer, rheumatoid arthritis, asthma), syndromes (for example downs syndrome, Emmanuel syndrome), Autistic spectrum disorder, attention deficit/hyperactivity disorder, developmental co-ordination disorder and acquired traumatic brain injuries. • Child not received physiotherapy or occupational therapy treatment. • Live outside UK
Physiotherapists & Occupational Therapists	• Heath Care Professions Council (HCPC) registered therapist. • Practising in UK • Least 18 months experience • Work with children with cerebral palsy • Working with children as they transition from primary to secondary school.	• Not HCPC registered • Practicing outside the UK • Do not work with children with Cerebral Palsy as part of their clinical caseload.

As further explained below, there were two rounds of data collection within the survey methodology. In each round, questionnaires were developed for the different participant groups. Final sample for round 1 was: caregiver (Cg1 [n=7]) and clinicians (Cl1 [n=56]). The clinician group was further categorised by profession (PT [n= 35] and OT [n=21]). Final sample for round 2 consisted of caregiver (Cg2 [n=4]) and clinicians (Cl2 [n=21]) further categorised into PT (n=12) and OT (n=9).

3.2 Data Collection Instrument

Data were collected using a self-complete online questionnaire. To meet study objectives, the questionnaires were designed to be open so that participants could provide full and honest accounts (Denscombe 2014). Review of current literature and practice highlighted no validated instrument to support the research question therefore two questionnaires were created, Cg1 and Cl1 (Appendix 2). Participant responses were used to guide the development of Cg2 and Cl2 (Appendix 3). Careful consideration was taken during questionnaire design to ensure items were as valid, reliable and acceptable for the study's descriptive nature (Sim and Wright 2000).

Considering design, it was necessary to ensure the questionnaire was easy to navigate and length short whilst not detrimental to data collection (Thwaites Bee and Murdoch-Eaton 2016). To assist with direction, visual elements such as bold font and colours were used (Groves et al. 2004:235). Automated routes and edit checks were used to reduce user error, exclude incomplete data sets (unless accounted for) and ensure the questionnaire was completed in full whilst safeguarding participants from answering questions that were not relevant to them (Groves et al. 2004:145). Inclusion criteria, relevant to each group, was placed at the beginning of Cl1 and Cg to ensure only participants with relevant experiences proceeded (Patton 2002). Embedded participant information sheets (Appendix 4a and 4b), specific to each participant group, and consent forms (Appendix 4c) followed to ensure participants were fully informed about the aims and objectives of the study (International conference on harmonisation 1996).

Closed-questions were used to collect demographic data (Sim and Wright 2000). Where categorise were used, care was taken to ensure they were mutually exclusive, for example when asking for clinician years of experience (Sim and Wright 2000). Checklists were used in both questionnaires when asking about current information provision (Sim and Wright 2000). Clear statements were used prior to ensure that the participant understood they were to check all items which applied to them. Checklists were comprehensive to ensure adequate choices however an 'other' box was provided giving participants the opportunity to reply in terms of a category not listed (Groves et al. 2004, Krosnick and Alwin 1999, Sim and Wright 2000). Questions following those collecting quantitative data, were open-ended in nature, collecting qualitative data, providing participants with an opportunity to present their experiences in their own words adding depth and further insight into responses (Bryman 2016, Sim and Wright 2000) This

approach to questionnaire design generated manageable amounts of data whilst not limiting participants opportunity to share experiences (Sim and Wright 2000:75).

Questions were worded using the fog index to ensure an appropriate reading level for participants and where possible terminology was non-technical (Matthews, Fox and Hunn 2009, Sim and Wright 2000). Neutral vocabulary was used to reduce potential bias and presence of loaded questions (Sim and Wright 2000). Both Cl1 and Cg1 were reviewed by experts in the topic of interest, one PT and one OT as part of a pilot procedure, to evaluate the face and construct validity of the questionnaire (Bolarinwa 2015). Construct validity of each questionnaire was achieved through use of NICE (2017) guideline recommendations around information use, with each question scrutinised to ensure it was relevant to understanding current practices of PTs and OTs and current experiences of caregivers (Cook and Beckman 2006).

As Cl1 and Cg1 provided a descriptive account, Cl2 and Cg2 were used as a form of respondent validation whilst gaining further understanding of the issues highlighted within the first questionnaires (Sim and Wright 2000). Cl2 and Cg2 collected both quantitative and qualitative data formed around first-round participant responses, to gather opinions on notable findings. Qualitative analysis of Cl1 and Cg1, as outlined below, generated categories such as barriers and challenges associated with information provision. Barriers were presented in Cl2 and Cg2 in three categories using ranking procedures (Sim and Wright 2000). It was important that ranking questions had minimal items to avoid confusion for participants. Clear information was given before the questions and embedded checks were used to stop participants ranking two items the same. Participants were able to leave questions blank to indicate they did not consider the item a barrier. An explanation that items left blank would be interpreted in this way was provided. Once data had been exported, missing data was appropriately coded for each variable to ensure accurate statistical analysis (Bryman 2016:332).

Likert scales were used to measure participants attitudes towards the qualitative statements drawn from first-round analysis. Attitude measurements focused on positives of information provision and solutions to overcome the listed barriers to information provision. Multi-item scales were used to provide a summative scale of the participants views (Sim and Wright 2000).

3.3 Procedure

3.3.1 Ethics and Governance

Ethical approval for the study was granted by Coventry University (P61846) (Appendix 5a). As participants were not recruited through the NHS, full NHS Ethical approval was not required. This was confirmed through liaison with the researcher's clinical trust Research and Innovation manager, West Midlands Clinical Research Network and through use of the Health Research Authority (HRA) decision tool (Appendix 5b).

3.3.2 Pilot

Following design, a pilot questionnaire was shared with an expert panel of one PT and one OT, recruited via convenience sampling. As suggested within Sim and Wright (2000) the pilot questionnaire was used to identify any problems with the content or functionality of the questionnaire whilst strengthening the questionnaire through review of its face and construct validity. Pilot participants received a pilot letter as invitation to participate (Appendix 6a). Due to ethics and accessibility, caregivers were not piloted however the expert panel were asked to comment on the content and usability of the cg1. The panel were asked to complete cl1 in full and asked to complete additional pilot questions (Appendix 6b). Questionnaires were altered and finalised following this feedback. Data from pilot responses were not used in the final analyses.

3.3.3 Questionnaire distribution

Gatekeepers were used to create a layer of safeguard between participants and the researcher, adopting a naturalistic approach with as little influence of the researcher as possible (Denscombe 2014, McFadyen and Rankin 2016, Sim and Wright 2000). Gatekeepers were provided with detailed information about the study aims and design, so they fully understood their role within participant recruitment. Gatekeepers were provided with a short advert with embedded link, open for approximately 6 weeks, which they were able to share however they deemed appropriate (Appendix 7a and 7b). Gatekeepers for the clinician group were defined as professional networks/organisations and for the caregivers' group were defined as non-statutory/voluntary organisations who support children with CP. After receiving the survey link, potential participants self-selected to participate. In line with descriptive survey approach there was no random allocation of participants (Sim and Wright 2000:71).

Participants who completed Cl1 and Cg1 were asked to consent to direct contact for second-round questionnaires. Consenting participants submitted their email address and

a clear statement that their responses were no longer anonymous was provided. Second-round questionnaires were open for approximately 6 weeks with one reminder email during this time to increase response rate (Braithwaite et al. 2003)

3.3.4 Data Management

Data was handled in accordance with the Data Protection Act (2018, c.12). Data was stored in line with the University Data Management policy (Coventry University 2017) following a data management plan (Appendix 8). Raw data collected via Bristol online survey was saved on the system's dashboard. Electronic documents generated were stored on the researchers' password protected drive with paper documents stored under lock and key.

3.4 Quantitative Analysis

3.4.1 Analysis on Cl1 and Cg1

Analysis and comparisons were made solely on naturally occurring groups (Sim and Wright 2000:71). Since response rate for the caregivers' participant group was n=7, only descriptive statistics were used. Raw data was exported from Bristol online survey into statistical package for social sciences (SPSS). To initially focus on quantitative analysis, qualitative data were separated to generate a quantitative data set. Descriptive statistics were performed for both participant groups to demonstrate group characteristics. Measures of frequency including count and percentage were conducted to build a picture of each group's participant sample.

For Cl1, measures of frequency were categorised into profession (PT/OT) so professional differences could be seen and could guide further comparative analysis. Trends, associations and differences within the dataset were reviewed (Bryman 2016). In Cl1 differences between professional groups were analysed. Tests of statistical significance were performed on the data to show confidence in findings with all significant tests at the level of p=0.05. Contingency tables were generated to analyse relationships between variables with chi-squared tests performed to demonstrate the confidence in relationships. Due to the small sample size, for data where the expected cell count of the chi-squared tests was less than 5, the fisher's exact value was reported to improve accuracy (Bryman 2016). As the data examined was non-parametric in nature, Spearman's rank-order correlation was used to demonstrate strength and direction of association between two variables and Mann-Whitney U tests were used to compare groups where the dependent variable was ordinal.

3.4.2 Quantitative Analysis on Cl2 and Cg2

Descriptive statistics were undertaken on Cl2 and Cg2. Measures of frequency presented as percentages, were performed for questions pertaining to measures of attitude. For questions where ranking scales were used, ranks were translated into a 'points scoring system' to demonstrate a cumulative score for each barrier. The points scoring system was adjusted depending on the number of items in the ranking question. For example, on a ranking question with 10 items, barriers ranked as the most impactful were scored 10 points, items ranked second 9 points and so forth with items ranked 10 scoring '1' point on the scale. From this, the spread of data for each item was reviewed showing the variability or conformity of responses. As this was performed for both Cl2 and Cg2 comparisons between clinicians and caregivers ranking were viewed.

3.5 Qualitative analysis

3.5.1 Analysis on all 4 questionnaires

It was not compulsory for participants to provide qualitative responses to any of the questions; participants were invited to respond only if they felt they had more information to add. As a result, a relatively small amount of qualitative data was captured, such that thematic analysis was not appropriate for this study. Therefore, the process of content analysis was deemed an appropriate method to review qualitative responses gleaned from all four of the questionnaires as the scope of written text gathered was limited (Bryman 2016).

Responses were read by the researcher, key terms highlighted and ordered into mutually exclusive categories (Appendix 9). Categories were created until saturation was reached for each question. Categories from Cl1 and Cg were used to formulate statements used in Likert and ranking scales in Cl2 and Cg2. For Cl2 and Cg2, participants qualitative responses were viewed and highlighted to establish key terms or repeated terms. Despite the small amount of qualitative data, responses were considered valuable to provide a deeper understanding to the quantitative data drawn from both the first-round and second-round questionnaires and were therefore used to support key messages highlighted from the quantitative data.

4 Results

4.1 Response rate

4.1.1.1 Clinician response – Cl1

Cl1 was accessed 132 times, demonstrating successful distribution of the questionnaire link, however, as the profile of those accessing the link could not be verified until the process of screening was completed, it was not possible to confirm that all these incidents of access reflected potential participants. Therefore, the screening process was used to establish the initial population for the study as follows: 24 potential respondents did not go past the introduction page (potential population=132-24=108); 33 people did not progress past the inclusion/exclusion screening items (108-33) giving an initial population of 75, verified as suitable to the study once consent had been confirmed. From the initial population of 75 participants, 19 participants failed to submit their response however a sample of 56 participants (PT[n=35]; OT [n=21]) completed the questionnaire, generating a response rate of 74.67%.

4.1.1.2 Caregiver response – Cg1

Cg1 was successfully distributed through the chosen gatekeepers, being viewed on the Bristol online survey platform by more than 1200 potential participants. Initial information provided about the study was robust and gave participants the opportunity to decide whether the survey was appropriate for them. Despite the fact that over 1200 potential participants accessed the survey (confirming successful distribution), this number cannot be considered reflective of the potential study population or sample, since this was an open link and anyone could have clicked on it. The potential sample could only be established from those who verified membership to the study population group through confirmation of the inclusion and exclusion criteria in the screening process.

Of those who clicked on the link, only 47 people proceeded to review the introductory information. Of those initial participants, 33 were screened out due to not progressing past the inclusion/exclusion screening items or not providing consent. As such, an initial verified population of 14 potential participants proceeded. From this, a sample of 7 participants completed the questionnaire, providing a 50% response rate based on the verified potential population.

Considering the health literacy of potential participants accessing the above caregiver questionnaire link, it is possible that the language and style of the information presented

in the introductory page and patient information sheet may have been too complex. The complexity and the length of the provided information may have in turn discouraged potential participants to continue with the rest of the questionnaire attributing to the high attrition rate from the 47 who viewed this information to the initial verified sample.

4.1.1.3 Second-round questionnaire response – Cl2 and Cg2

Consenting clinicians (n=36) were directly sent the link to Cl2. All 36 participants accessed the questionnaire, 8 participants did not progress to start the questionnaire and 7 did not submit their responses. 21 participants (PT [n=12]; OT [n=9]) completed the questionnaire, giving a response rate of 58.33%.

Cg2 was sent to consenting caregivers (n=4). All 4 participants accessed the questionnaire however 2 participants failed to submit their responses. 2 participants completed with questionnaire giving a response rate of 50%.

4.2 Respondent demographics

4.2.1 Cl1

Three out of four UK countries were represented with most participants living in England (n=47) followed by Scotland (n=8) and Wales (n=1). No respondents resided in Northern Ireland. 71.4% of clinicians had over 10 years' experience working with children with CP at the point of transition; less than 10% of the clinicians had less than 5 years' experience. The experience of clinicians was represented by clinical grades with 76.8% of clinicians working at band 6 (senior) or band 7 (specialist) level. There were no band 5 (junior) or band 9 (consultant) respondents. One respondent identified as a 'locum' therapist holding the least experience, working with children with CP for 18 months to 2 years. Three PTs and 2 OTs worked in private practice and all with more than 5 years' experience. 62.5% of clinicians reported working with children of all GMFM levels.

4.2.2 Cg1

Seven mothers responded to cg1, representing three out of the four UK countries. There were no respondents from Northern Ireland however the caregiver response was more spread; England (n=2); Scotland (n=1) and Wales (n=4). All participants identified their children to have a primary diagnosis of CP, with 3 participants reporting an acquired brain injury before the age of 3 to be the cause.

Four out of the seven caregivers did not provide the gross motor function measure (GMFM) to classify their child's CP however could describe the nature of their child's CP. Classification of type of CP is outlined in Table 2 with GMFM level used where available.

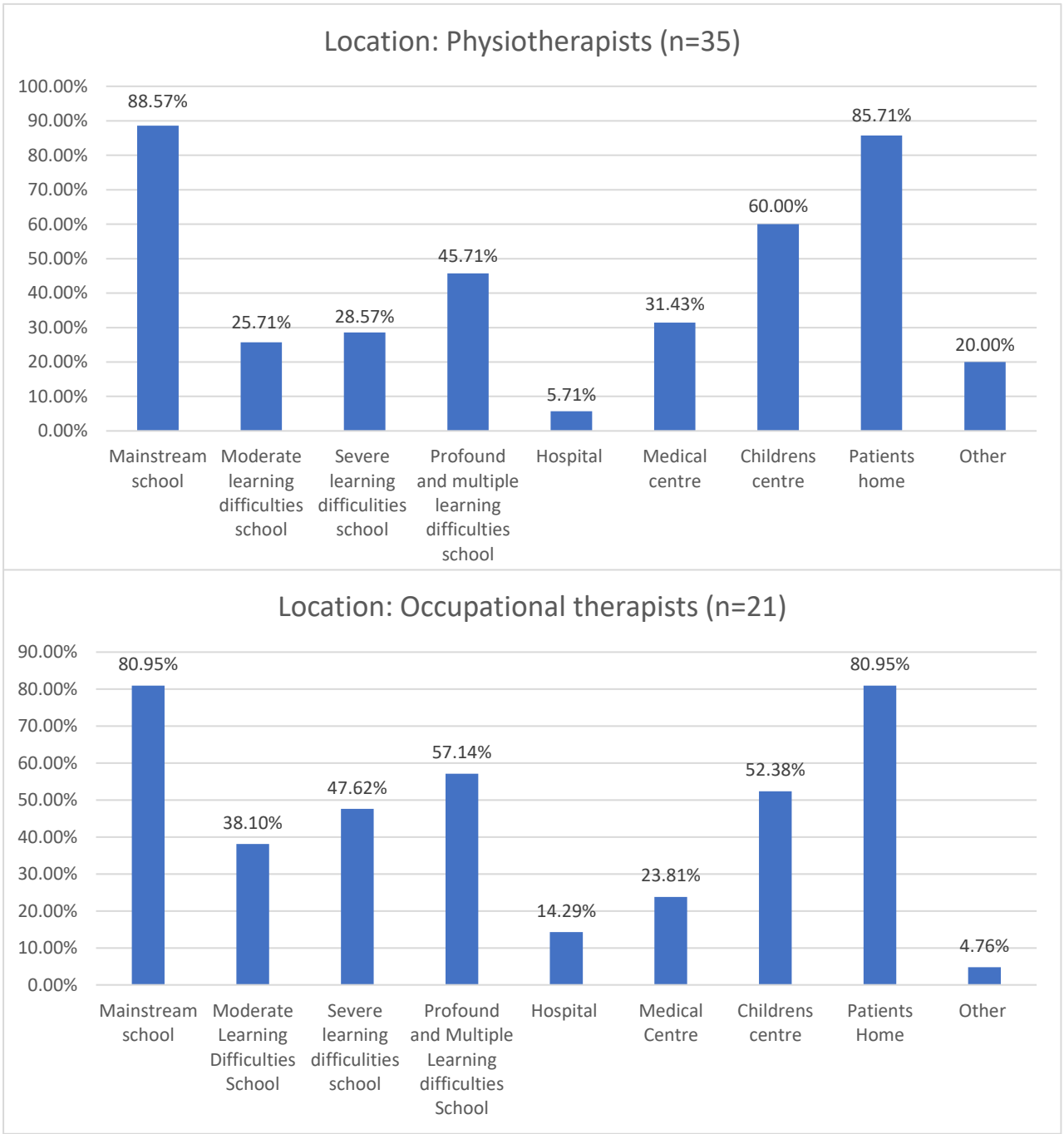
Table 2 - Classification of CP

Participant	**Classification/description**
1	Hemiplegic
2	Dyspraxic
3	Hemiplegic
4	Ataxic
5	GMFM Level 2 – Hemiplegic
6	GMFM Level 2 – Spastic diplegic
7	GMFM Level 4 – Quadriplegic

4.3 Location of therapy

Clinicians highlighted that they provided therapy in many locations (Figure 3). Clinicians indicated working in 9 out of the 10 locations listed with no clinicians (PT or OT) working in a Doctors surgery. Clinicians stated other areas as respite care centres, wheelchair services clinics and although not relevant to children at transition to secondary school reported working in nurseries.

Figure 3 - Location of therapy



All caregivers (n=7) reported that their children attended mainstream school. Six out of the 7 children received their PT at school and 5 out of 7 received OT at school. One caregiver reported that both OT and PT provision had ceased following transition to secondary school however did not provide a reason for this.

4.4 What information is currently provided by PTs and OTs to caregivers of children with CP as they transition from UK primary to secondary education.

4.4.1 NICE guideline topics

Both participant groups were asked about their current information habits, caregivers in receiving information and clinicians giving information. Clinicians were first asked to consider the NICE guidelines (2017) topics of information. Both therapist groups reported providing information on all NICE guideline topics, outlined in table 3, however clinicians demonstrated topics of information which they felt more confident providing information.

Table 3 - Comparison between clinician provision of NICE guideline topics

NICE Topics	PT (n=)	OT (n=)	Chi-squared	p=<0.05*
Diagnosis	27 (77.1%)	11 (52.4%)	3.69	0.05
Prognosis	28 (80%)	10 (47.6%)	6.31	0.01*
Expectation	33 (94.2%)	15 (71.4%)	5.60	0.04*†
Co-morbidities	19 (54.2%)	9 (42.9%)	0.69	0.41
Availability of specialist equipment	34 (97.1%)	19 (90.4%)	1.15	0.55†
Access to financial support	16 (45.7%)	9 (42.9%)	0.04	0.84
Access to respite care	16 (45.7%)	10 (47.6%)	0.02	0.89
Access to social care	18 (51.4%)	8 (38.1%)	0.94	0.33
Educational Placement	24 (97.1%)	14 (66.7%)	0.02	0.88

† Fishers exact used

Between group comparison demonstrated that there was statistically more PTs providing information on two topics; prognosis and expectations. To determine if there was a relationship between years of experience and the number of information topics PTs and OTs provide, spearman's rank correlation was performed. Results (r_s =0.01, p=0.98) demonstrated no significant relationship between these two variables.

4.4.2 Provision of therapy-specific information

In the first-round questionnaire clinicians were asked to consider if they provided any therapy-specific information at transition to secondary school. The number of clinicians providing information about each topic was directly compared to determine any differences between the topics each profession provided information on. The table is colour coded in the following code for clarity.

Table 4 - Clinicians provision of therapy-specific information

Blue = significant difference PTs (PTs provide more information)

Green = significant difference OTs (OTs provide more information)

Yellow = No significance between profession but both providing information

Orange = No significance between profession but few clinicians providing information

Topics	PT (n=)	OT (n=)	Chi-squared	p=<0.05*	Mann-Whitney U	p=<0.05*
Transfers	30 (85.71%)	17 (80.95%)	0.22	0.72†	172.00	0.27
Toileting	10 (28.57%)	19 (90.48%)	20.15	<0.001*	365.00	0.58
Washing	1 (2.86%)	16 (76.19%)	33.39	<0.001*	307.00	0.58
Dressing	2 (5.71%)	18 (85.71%)	33.19	<0.001*	337.50	0.63
Exercises (PT)	32 (91.42%)	3 (14.29%)	33.24	<0.001*	364.50	0.95
Exercise (OT)	0 (0%)	13 (61.90%)	28.22	<0.001*	235.00	0.26
Walking	30 (85.71%)	6 (28.57%)	18.67	<0.001*	356.50	0.94
Stairs	29 (82.86%)	12 (57.14%)	4.43	0.04*	290.00	0.68
Access to leisure	25 (71.43%)	15 (71.43%)	0	1	310.50	0.83
Access to buildings	24 (68.57%)	16 (76.19%)	0.37	0.54	310.50	0.83

Aids for eating/drinking	4 (11.43%)	19 (90.48%)	33.89	<0.001*	333.00	0.33
Aids to assist with work	2 (5.71%)	18 (85.71%)	36.59	<0.001*	336.50	0.63
Use of splints/orthosis	29 (82.86%)	12 (57.14%)	4.43	0.04*	264.00	0.31
Social interaction	13 (37.14%)	7 (33.33%)	0.08	0.77	345.00	0.75
Self-organisation skills	11 (31.43%)	14 (66.67%)	6.60	0.01*	386.50	0.98
Female menstruation support	1 (2.86%)	9 (42.86%)	14.32	<0.001*	202.00	0.45
Mental health support	1 (2.86%)	2 (9.52%)	1.15	0.24	77.50	0.93
Behavioural support	1 (2.86%)	3 (14.29%)	2.59	0.11	98.00	0.81
Emotional support	5 (14.29%)	4 (19.10%)	0.22	0.64	205.50	0.87
Other (Please state)	5 (14.29%)	4 (19.10%)	0.22	0.64	191.50	0.57

† Fishers exact used

A Mann-Whitney U non-parametric test determined no association between the years a clinician had been working with children with CP and topics of information provided. On analysis there was no reason provided for the inter-professional differences. Thus, the second-round questionnaire was used to share notable findings with both participant groups to gain their opinions.

4.4.3 Information at transition to secondary school

51 clinicians (91.07%) (PT [n=32]: OT [n=19]) provided information at transition to secondary school. Mann-Whitney U test determined that there was no significant difference ($p = 0.203$) between the years of experience and provision of information at transition. There was also no significant association ($p = 1.000$) between the clinician's location within the UK and information provision at transition.

Four out of the 7 caregivers had received information from clinicians (PTs/OTs) during their child's transition to secondary school with all of them finding this useful. Despite this, 4 out of the 7 caregivers reported they would like more information. The 3 caregivers who did not feel they needed more information attributed this to the provision of written information. In Cg1 (n=7) were asked if they would like to receive more information on any of the therapy-specific information topics, at least one caregiver requested more information on all topics. Considering the low response rate, it is not possible to ascertain how representative the views are of the wider population. Therefore, to investigate this further, the Cg2 prompted caregivers to further explore their need for information at the transition to secondary school. Caregivers reported that they had requested more information on these topics as they felt they were particular *'challenges for schools and few central resources to help'*.

4.4.4 Qualitative findings around what information is currently provided by PTs and OTs to caregivers of children with CP as they transition from UK primary to secondary education.

In the second-round, clinicians and caregivers were asked if the differences between the professional groups providing therapy-specific information were 'expected'. In Cl2, clinicians (n=21) agreed that 5 out of 8 topics which OTs provided more information on and 2 out of the 4 topics where PTs provided more information were 'expected'. Qualitative responses demonstrated some debate regarding PTs providing information on completing the stairs and provision of splints. In Cg2, 6 out of the 8 topics where OTs provided more information considered 'expected' and all topics were considered 'expected' for those where PTs provided more information.

Although all topics of therapy-specific information were covered by both PTs and OTs there were some topics that very few clinicians focused on highlighting neglected topics. When asked to provide reasons for reduced provision on the 4 topics (mental health support, behavioural support, emotional support, social interaction support) clinicians felt that these were covered by other services such as education and services such as children and adolescence mental health service (CAMHS). Clinicians highlighted difficulties with receiving services such as CAMHS with '*long waiting times'* from referrals and challenges in meeting the referral criteria. Clinicians reported that their *'lack of knowledge'* about topics meant they did not provide information, with some participants reporting that there is a *'lack of training'* for staff on these issues and availability of the services in their local area. Clinicians reported time as a barrier to providing information

reporting that the *'level of their caseload'* had an influence on the amount of information provided.

When considering the neglected topics, participants felt that providing information would be out of their *'scope of practice'*, reporting for example that the topic of female menstruation support should be dealt with by a *'school nurse, GP or community nurses'*. Although a topic significant to OTs, female menstruation support, had a low number of clinicians providing this information. When asked about the topic of female menstruation support 23.8% of clinicians did not know what to expect. For all topics, participants felt that these areas were not part of their *'core role'* yet stated they would signpost if they had relevant information and service specific knowledge.

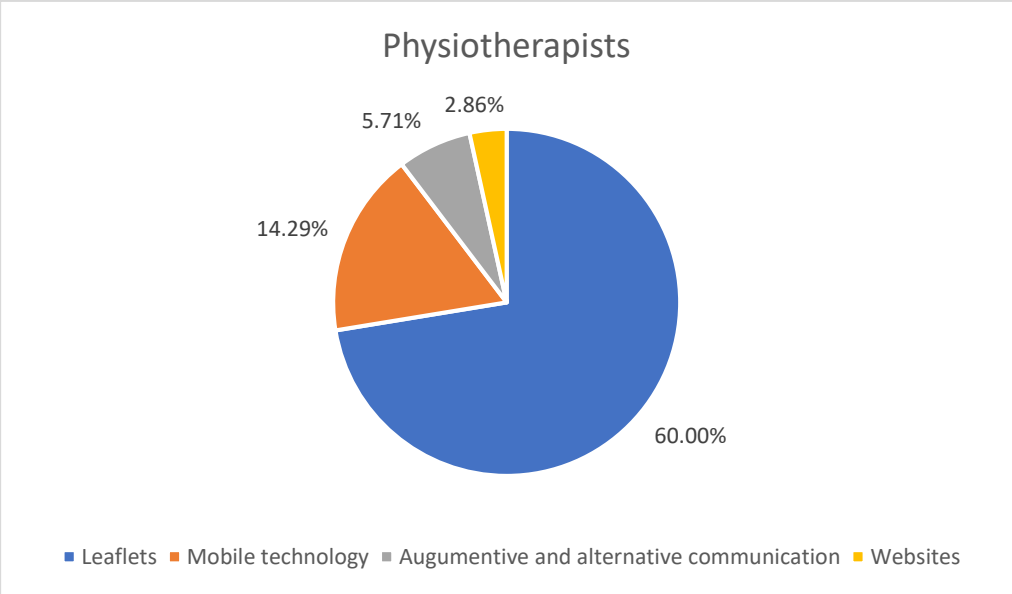
Caregivers were asked to comment on what they felt the barriers could be to clinicians providing caregivers with information of the highlighted neglected topics. Responses mirrored the clinicians' views. In response to provision of information about mental health support, one caregiver highlighted that *'people are reluctant to signpost to services that are notoriously under resourced',* with both caregivers reporting their perceived barrier to be the availability of services. For the topics of behavioural and emotional support, caregivers felt that *'staffing'* and '*money'* were limitations to them receiving information. However, when considering female menstruation support, one caregiver highlighted the '*taboo'* nature of the topic, stating that this topic is generally overlooked and personally having received '*no* support' suggested that the provision of this information should potentially be the role of the Paediatrician.

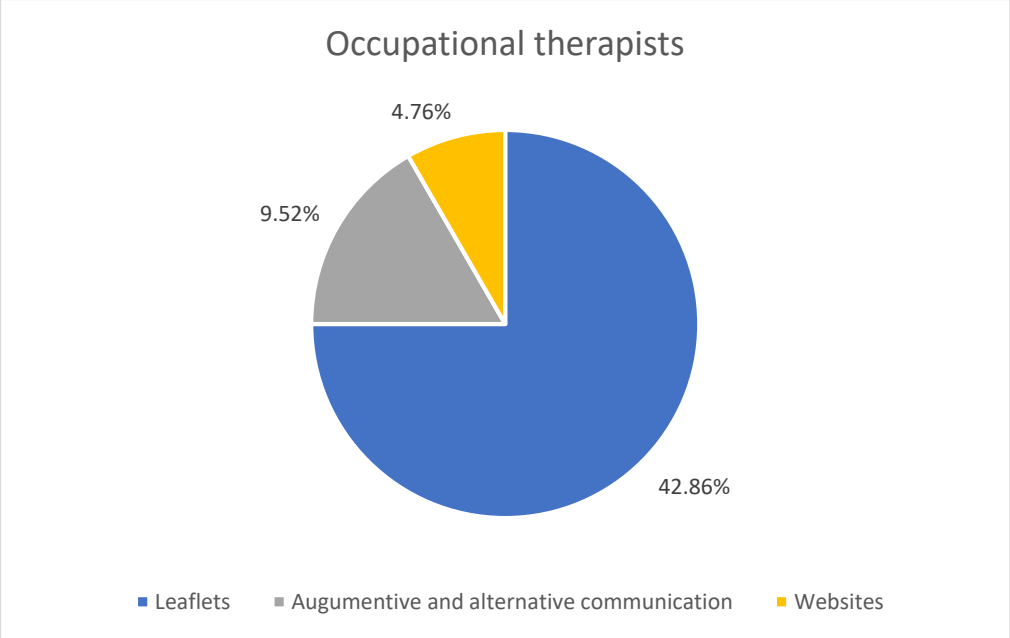
Caregivers commented on the difficulties faced with gaining information to help with their child's social interaction noting it as '*so challenging and a low priority for healthcare providers'*. As was highlighted in the response of the clinicians, caregivers highlighted that most healthcare providers '*think schools will deal with this one'*. Caregivers requested more information on all of the stated therapy-specific topics, attributing this choice to their concerns that access to this information was a '*challenge for schools'* with '*few central resources to help'*.

4.5 How information is currently provided by PTs/OTs to caregivers of children with CP as they transition from UK primary to secondary education.

Caregivers reported a mix of how they received the information given to them by therapists at transition, including verbal (n=3), written reports (n=3) and leaflets (n=2). 100% of clinicians (PT [n=35]: OT [n=21]) reported providing verbal information to caregivers. Written information was provided by 77.14% of PTs and 66.67% of OTs. Clinicians reported using a variety of methods which they used to provide information, outlined in figure 4.

Figure 4 - Methods of information provision





Two out of the 3 caregivers received a written report stating that documentation of their child's needs helped them to *'make arrangements prior to starting high school'.* One caregiver reported the use of leaflets as good practice stating these were *'easy to read and* understand'. However, despite receiving written information, one caregiver found this unhelpful as the information was provided on carbon paper meaning the information was illegible. 5 out of 7 caregivers requested simplified verbal information so they could *'understand it well'* and wished to be provided with an opportunity to ask questions. Caregivers believed receiving information in this manner would enable a sense of

preparation for transition for both the child and parents. Caregivers highlighted the benefits of written information reporting how it *'documents specific needs'*, are good to *'keep for future reference'* and how they appreciate information that can be '*accessible at any time'*.

4.5.1 Use of 'patient folders' in clinical practice

When thinking about the suggested topics from the NICE guidelines (NICE 2017), participants were asked to consider the use of a 'patient folder'. On average, 73.2% (PT [n=25; 69%] and OT [n=16; 76%]) of clinicians reported they did not use a patient folder. When asked to demonstrate their understanding of a 'patient folder' and its use in clinical practice PTs [n=6; 16.6%] and OTs [n=5; 23.8%]) reported that they *'didn't know'*, *'had not heard the phrase before'* or were *'unsure'* of the meaning of the term or were *'unaware that this was expected'*.

15 clinicians reported using 'patient folders' in clinical practice. For participants who had used a 'patient folder' there were both positive and negative experiences. One clinician found that it *'gives the patient (if able) and the family a way to 'take control' of their situation and experiences'*. Responses demonstrated a mix in clinicians understanding of what a 'patient folder' was and what format it should be. As a way of providing information to caregivers, clinicians reported that 'patient folders' can be '*useful where a number of professionals are working with the same child'* with a *'paper-light central system'* working *'better than a physical paper folder'.* Clinicians highlighted the need and benefit of having '*all patient info in one location to enable effective integrated service delivery'*.

Despite these suggested benefits, some participants presented barriers to the use of a 'patient folder' highlighting that although a *'great idea'* it was not something that was used by the *'statutory providers'* in their area. Some clinicians reported using patient folders can often be '*bulky and awkward to transport to appointments'*.

4.6 Gaps in the nature and means of current information provision

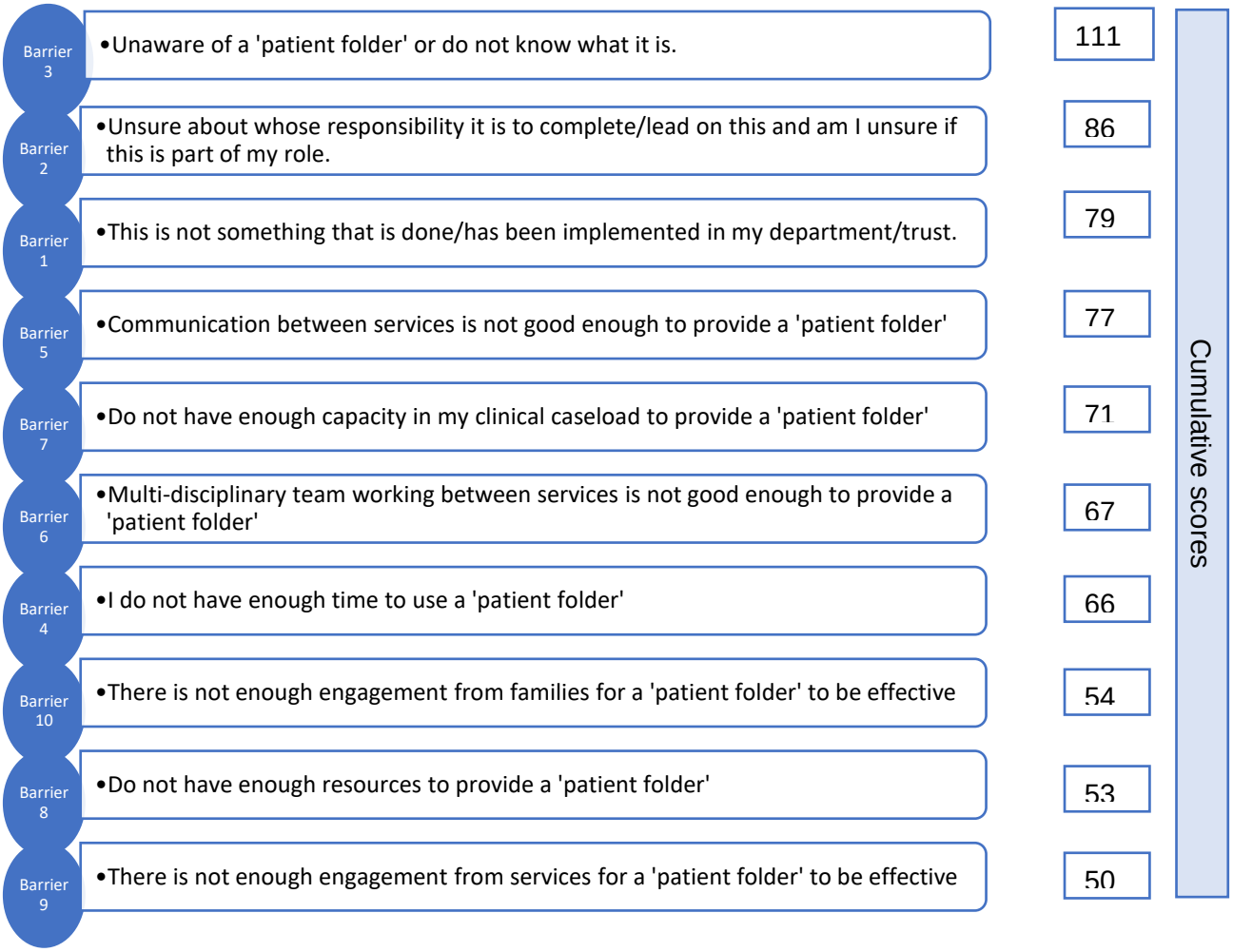
Using the qualitative data from Cl1 and Cg1, specific barriers were drawn out. 10 barriers specific to the use of patient folders and 15 barriers to information provision at transition. Barriers to information provision at transition were further categorised into barriers associated with healthcare provision (n=7), barriers associated with education provision (n=6) and barriers associated with caregivers/children (n=4). Barriers were presented to clinicians and caregivers in Cl2 and Cg2. Caregivers were not asked to comment on the

barriers to the use of patient folders as barriers presented from CI1 were pertinent to practical use in clinical practice. However, caregivers were asked in Cg2, if they had experience of the use of a patient folder with caregivers (n=2) responding ‘no’ however both reported they felt this would be a helpful concept.

4.6.1 Clinicians views on the barriers to the use of a ‘patient folder’

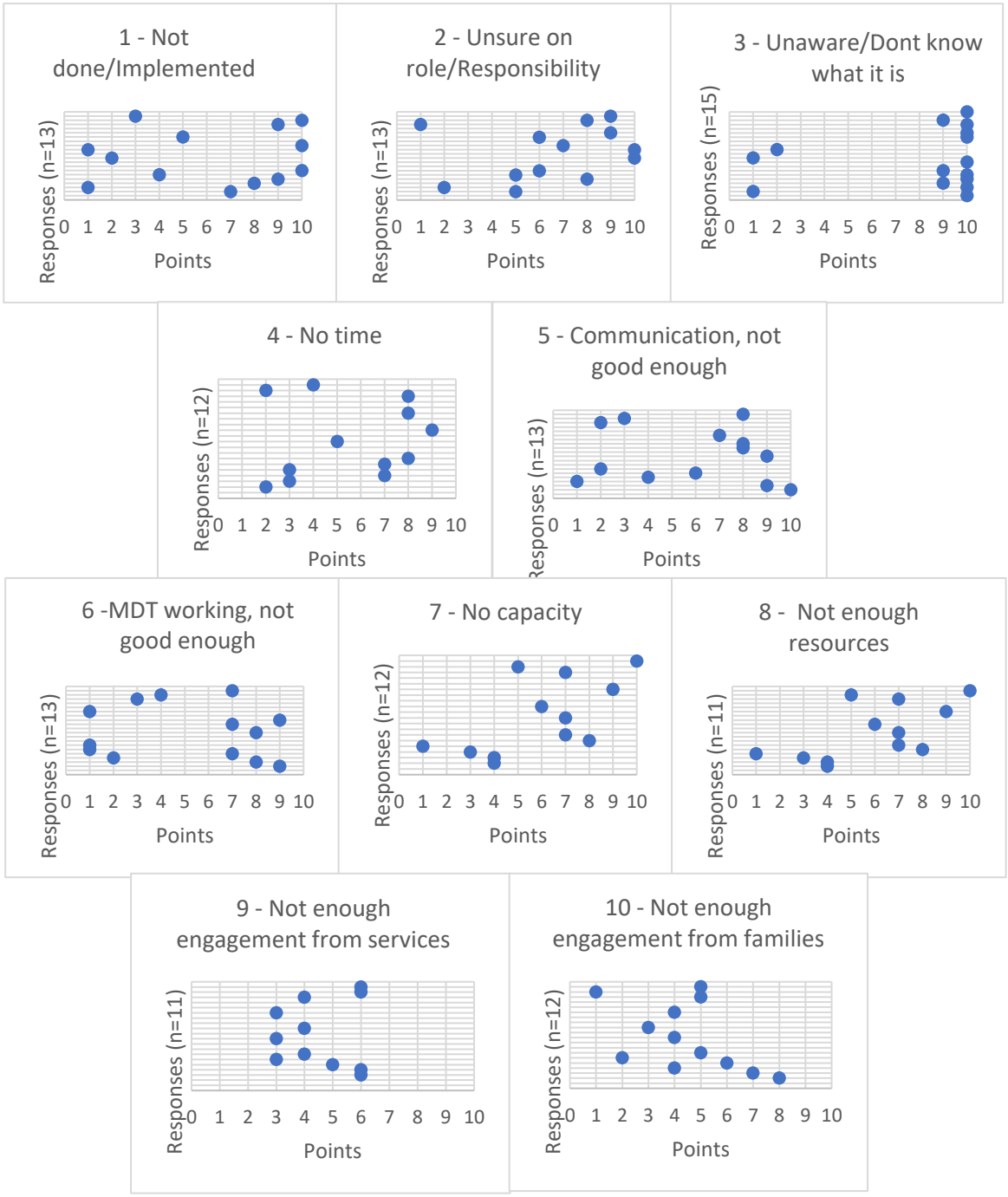
21 Clinicians (PT[n=12]: OT[n=9]) responded to the CI2 and were asked to clarify the significance of each barrier to their use of a ‘patient folder’ in their current clinical practice. Cumulative scores, generated from the ranking system outlined in the data analysis section 3.4.6, were then ordered to identify the highest and lowest ranked barriers overall from the clinicians who responded, presented in figure 5.

Figure 5 - Barriers to using a 'patient folder' in clinical practice



The agreement of therapists as to how impactful each barrier was to their clinical use of a ‘patient folder’ can be viewed in the spread of responses. The distribution of the responses for each barrier is demonstrated below using scatter plots in Figure 6.

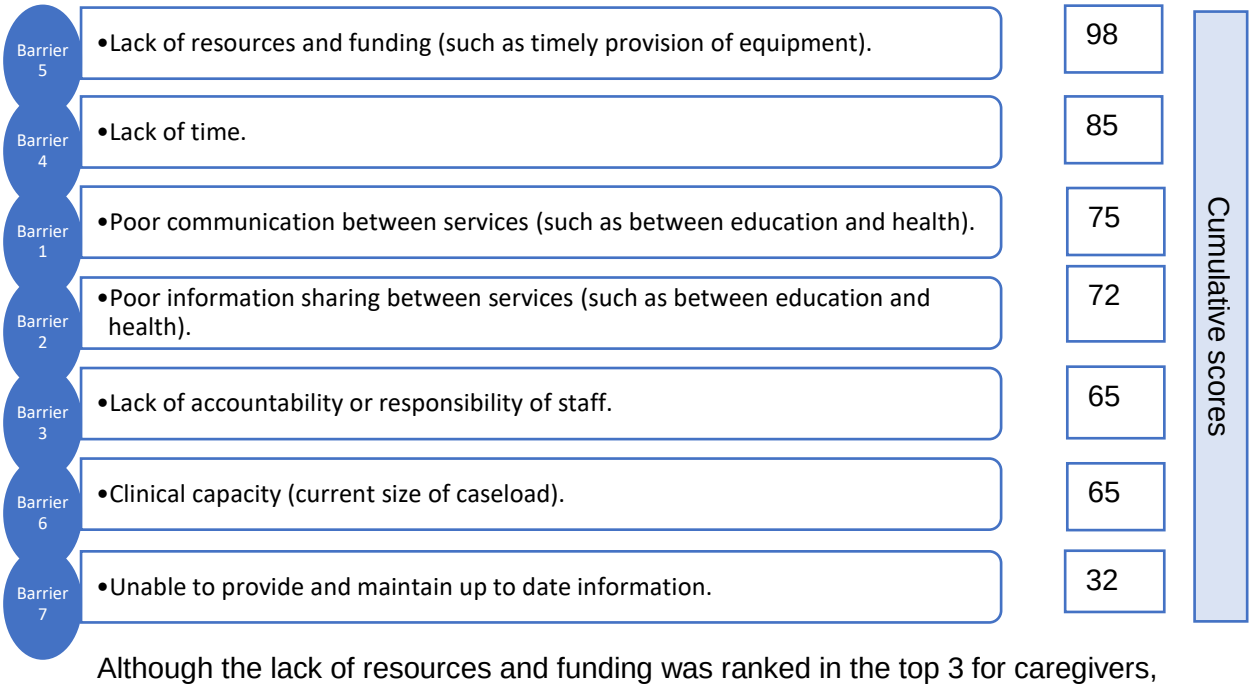
Figure 6 - Spread of responses for barriers of using patient folders in clinical practice



4.6.2 Barriers to information provision at transition to secondary school.

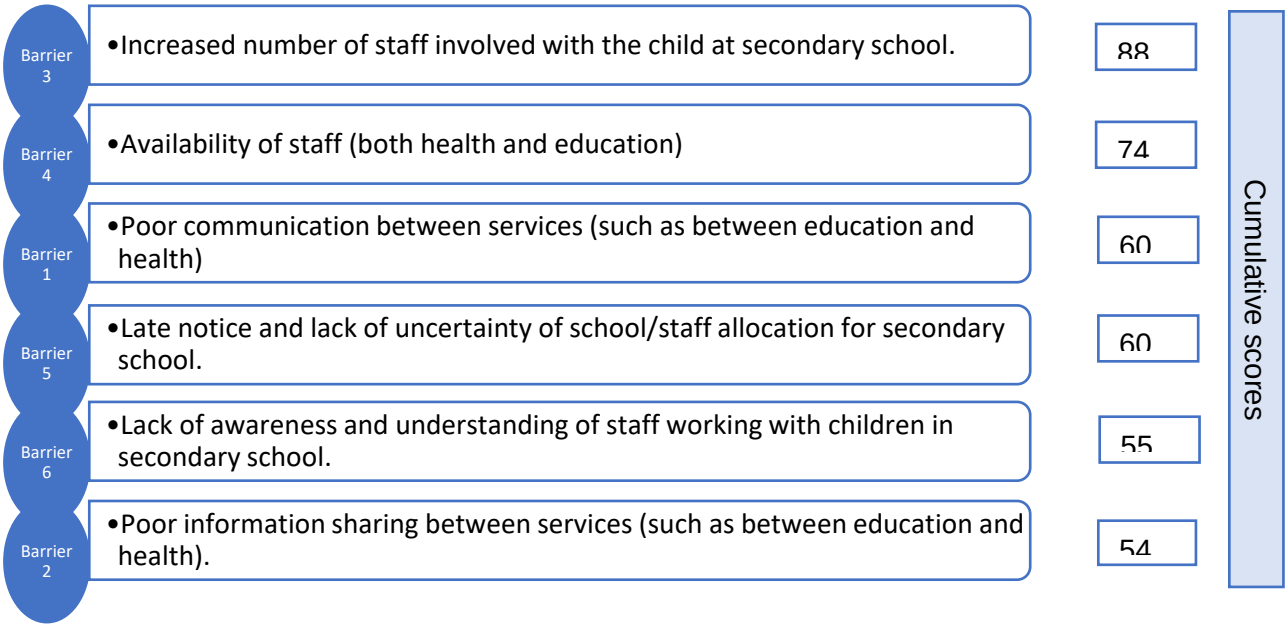
In Cl2 and Cg2 participants were asked to comment on the barriers, ranking them from highest to lowest barriers overall. Figure 7, 8 and 9 demonstrate the cumulative ranking of clinician group only on the three areas of barriers pertaining to information provision.

Figure 7 - Barriers to information provision associated with healthcare services



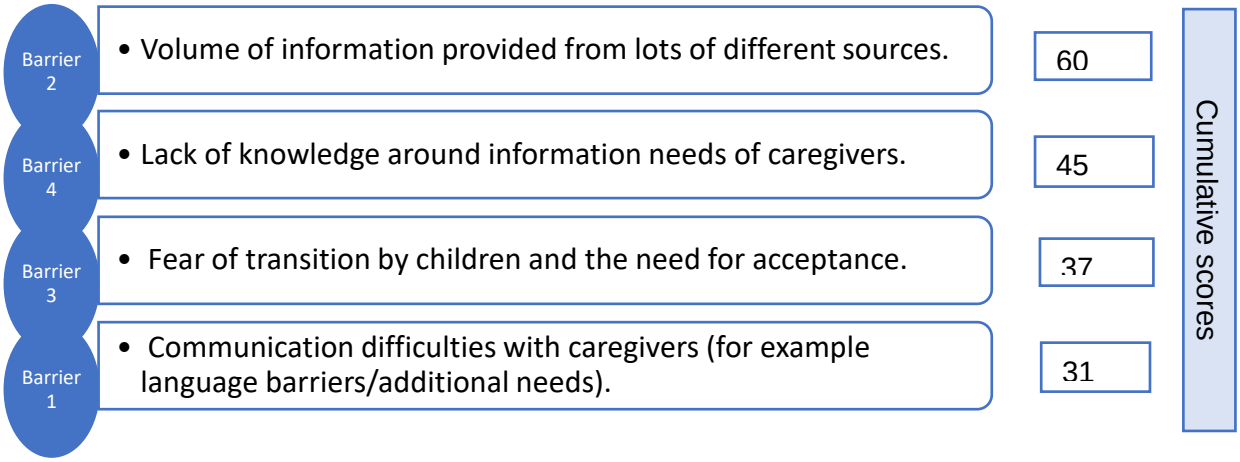
Although the lack of resources and funding was ranked in the top 3 for caregivers, the lack of clinicians' time was considered the most impactful barrier to caregivers receiving information at transition.

Figure 8 - Barriers to information provision associated with education provision



Once again, caregivers (n=2) disagreed with clinicians as to the most pertinent barrier, ranking the increased number of school staff involved with the child at secondary school 2nd. Caregivers felt that the lack of awareness and understanding of staff working with children in secondary school was the most impactful to them. Further mismatch in consideration of the barriers between clinicians and caregivers can be seen in the barriers associated with caregivers/children.

Figure 9 – Barriers to information provision associated with caregivers/children



In contrast to clinicians, caregivers ranked the volume of information provided at transition as their least pertinent barrier reporting that both the lack of knowledge around information needs of caregivers and the fear of transition/need for acceptance of their children were more impactful to them.

Clinicians and caregivers were asked to determine which of the three areas of barriers was most impactful to their successful provision of information. 84.2% of clinicians felt that the barriers associated to education provision were the most impactful. This, however, varied for the caregivers with one reporting barriers of health provision and one reporting barriers of caregivers.

4.7 Experiences of positives of information provision and solutions for successful future information provision for CYP with CP at transition to secondary school

Clinicians and caregivers were able to appreciate the positives of providing information at transition. In the Cl1 clinicians highlighted several positives in providing information at transition. These findings were shared with participants in Cl2 and Cg2. For both positives and solutions for successful information provision, PT and OT suggestions and responses are considered together as the statements were not considered to be profession specific. However, the response rate for each profession is outlined in each table. Table 5 demonstrates the agreement of clinicians with each of the statements. No participants strongly disagreed with any statement.

Table 5 - Positives of providing information at transition

Positives	Strongly agree (%)	Agree (%)	Disagree (%)
Helps to create a smooth transition for the child. (PT [n=12] and OT [n=9])	*71.4*	*28.6*	
Improves the knowledge and understanding of people working with the child (PT [n=12] and OT [n=8])	*75.0*	*25.0*	
Gives people something to refer back to in future. (PT [n=12] and OT [n=9])	*47.6*	*52.4*	
Helps to inform and support people working with the child. (PT [n=12] and OT [n=9])	*71.4*	*28.6*	
Can help to improve the independence/inclusion/participation of the child at secondary school. (PT [n=12] and OT [n=9])	*61.9*	*33.3*	*4.8 (1)*
Can improve the continuity of care. (PT [n=12] and OT [n=9])	*71.4*	*23.8*	*4.8 (1)*
Can improve the outcomes/compliance of therapy. (PT [n=12] and OT [n=9])	*47.6*	*42.9*	*9.5 (2)*
Helps alleviate anxiety around transition (both staff and child) (PT [n=12] and OT [n=9])	*71.4*	*28.6*	
Useful for preparation prior to starting secondary school (PT [n=12] and OT [n=9])	*66.7*	*33.3*	

Caregivers in Cg2 (n=2) agreed or strongly agreed with 100% of the above statements. In Cl1, clinicians acknowledged that more input is needed to overcome the barriers

associated with information provision at transition into secondary school and suggested a range of solutions. These were collated in Cl2 and Cg2 to gain participants views on these suggestions. Table 6 outlines solutions suggested in Cl1 and clinician's agreement with these in Cl2.

Table 6 – Suggested solutions to overcome barriers to information provision at transition

Solutions (Response n=)	Strongly agree (%)	Agree (%)	Disagree (%)	Strongly disagree (%)
Protected time for staff (both health and education) at transition. (PT [n=11] and OT [n=9])	*50.0*	*50.0*		
Identified lead person. (PT [n=12] and OT [n=9])	*57.1*	*28.6*	*14.3*	
Use of pre-visits/meetings (PT [n=11] and OT [n=9])	*60.0*	*35.0*		*5.0*
Improved communication. (PT [n=12] and OT [n=7])	*47.4*	*47.3*	*5.3*	
Improved understanding of educational staff. (PT [n=12] and OT [n=8])	*45.0*	*55.0*		
Individualised information for education staff (PT [n=12] and OT [n=9])	*42.9*	*57.1*		
Reduced caseloads (caseload management). (PT [n=12] and OT [n=9])	*42.9*	*42.9*	*14.3*	
Generation of specific training for educational staff at transition. (PT [n=12] and OT [n=8])	*40.0*	*55.0*	*5.0*	
Increased pre-planning (prior to year 6 primary school) (PT [n=12] and OT [n=8])	*40.0*	*25*	*30*	*5.0*
Nationally produced standardised information/advice (i.e. apps/ leaflets/ website) (PT [n=12] and OT [n=7])	*36.8*	*42.1*	*21.1*	
Improvements in MDT approach and planning. (PT [n=12] and OT [n=9])	*33.3*	*47.6*	*19.0*	
Access to education staff in the summer holidays. (PT [n=12] and OT [n=9])	*28.6*	*38.1*	*28.6*	*4.8*
Buddy system/support system using other families. (PT [n=12] and OT [n=9])	*19.0*	*61.9*	*19.0*	

Protected time for staff (both health and education) to be able to provide information to caregivers was the most agreed upon statement. Caregivers also agreed this would be a beneficial solution to the current barriers. Caregivers agreed with clinicians' solutions of improved understanding of education staff and for using individualised information for staff in schools. Overall in Cg2, caregivers agreed with all clinicians' suggested solutions including the use of a buddy system during the transition. Once caregiver did not feel that improved communication or the use of nationally produced standardised information would be of benefit.

4.8 Qualitative responses considering the mismatch between clinicians and caregivers towards the barriers to information provision at transition to secondary school and solutions for successful future information provision.

The mismatch between caregivers' and clinicians' consideration of the most impactful barriers can be seen for each of the three sections, with caregivers ranking different barriers for every section. One caregiver commented that they had previously had difficulties with gaining information due to the '*the tendency of professionals to give more credence to other professionals' views than those of caregivers'* reporting this '*is a frustration at times'.* Despite this mismatch, caregivers commented on the importance of information at transition, reporting that is *'essential to provide information at transition. The problem is that this is occasional - it doesn't always coincide with changes and developmental milestones for the child and most children transition each year to new class teachers and helpers. More input is needed.'*

When considering the suggested solutions to overcome the barriers to information provision and the highlighted mismatch in priorities there was agreement between caregivers and clinicians. Caregivers stated that '*sharing contact details of families within the school would help'* and agreed that all other solutions would be of benefit to successful future information provision.

5 Discussion

5.1 Review of aims and objectives

This study aimed to describe the current PT and OT information needs of caregivers of children, living within the UK with a diagnosis of CP, during the transition from primary to secondary education. This aim was fulfilled by the following five objectives;

1. Describe what information is currently provided by PTs and OTs to caregivers of children with CP as they transition from UK primary to secondary education.

2. Describe how information is currently provided by PTs and OTs to caregivers of children with CP as they transition from UK primary to secondary education.

3. Capture and describe caregivers' experiences of good practice when receiving information from PTs and OTs regarding transition from UK primary to secondary education of children with CP.

4. Capture and describe gaps in the nature and means of information provision provided by PTs and OTs to caregivers of children with CP as they transition from UK primary to secondary education.

5. Identify caregiver-informed strategies for future information provision from PTs and OTs to caregivers of children with cerebral palsy as they transition from UK primary to secondary education.

The following discussion demonstrates how study findings met each objective. Guided by findings, objectives one and two are discussed together. Guided by response rate, objectives three and five are considered together. Study findings for each objective are considered in the context of Bronfenbrenner's (1979) ecological systems framework alongside relevant literature, to give further understanding to whether study findings demonstrate a current ecosystem and practice which is supportive to development and in this case the transition of children with CP to secondary school (Shelton 2018). The framework is used to guide recommendations for clinical practice to make changes, where required, to relationships, roles, settings or communities as elements of a child with CPs ecosystem to make it more developmentally facilitating (Bronfenbrenner 1979, Shelton 2018).

5.2 What and how information is currently provided by PTs and OTs to caregivers of children with CP.

When focusing on suggested NICE (2017) guideline topics study findings showed that clinicians had greatest confidence in providing information about access to specialist equipment. This could be explained as the provision of equipment for children with CP is considered a core part of a PT or OTs role, for example standing and walking frames (Novak et al. 2013, NICE 2013, NICE 2017). Study findings showed that PTs were more likely to provide information on topics, prognosis and expectations. As an explanation for this disparity was not an objective of the current study, reasons were not captured within the clinicians' questionnaire. The topics of prognosis and expectations could be considered future focused in nature and when considering healthcare management could be considered topics that medical professionals such as Doctors or Consultants may provide information on rather than clinicians such as PTs and OTs (Bindles-de Heus et al. 2013). Despite focusing on the role of Paediatricians in the transition to adult care, Bindles-de Heus et al. (2013) outlined caregivers' experiences of how lack of future-focused information was detrimental to a smooth transition. Clinically, the use of the items such as the Gross motor function measure (GMFM) may provide an explanation of PTs increased assurance to provide information about prognosis and expectations for children with CP (Rosenbaum et al. 2002). However, from this study it is not possible to deem how many of the participating clinicians use this tool in clinical practice meaning further research into the role of such clinical tools and their influence on clinicians' attitudes towards information topics would be required.

When reviewing current provision of therapy-specific topics, both PTs and OTs highlighted preferences towards provision of certain information topics, for example PTs providing information on walking or use of splints. Yet, it is notable that six information topics were not considered significant to either profession and had markedly lower clinicians providing information on these areas; mental health support, emotional support, behavioural support, support with social interaction and female menstruation. Clinicians considered topics as not being part of their core 'role' or outside their 'scope of practice' to be a reason why they did not feel equipped to provide this information. The HCPC (2013, 2013a) standards of proficiency for both PTs and OTs explores the concept of 'scope of practice' defining it as the clinician's ability to ensure they have the right knowledge and skills to practice safely, whilst maintaining the standards of proficiency. The HCPC (2013, 2013a) however, acknowledge that a clinician's 'scope of practice' will

vary between clinical specialities and discuss it as fluid in nature meaning with adequate training and knowledge a clinician may be able to provide information without it being outside their 'scope of practice'.

In this study, neither clinician group felt it was their 'role' to provide mental health support and caregivers were not sure who they should look to for this information. Both clinicians and caregivers highlighted the view that mental health services in the UK are under-resourced and it was difficult to gain these services for children with CP. Clinicians indicated the long-standing and ever-increasing conditionality, the necessity to prove need before service allocation, attached to these types of healthcare services (Dwyer 2004). In addition, increasing levels of qualifying criteria meant that access to services such as children and adolescence mental health services (CAMHS), was expressed as a growing concern for clinicians and caregivers. Access to these services may play a pivotal role for children with CP in the transition to secondary school who, as discussed in the literature review, may require additional support to alleviate anxieties associated with the ecological transition into a new setting (Bronfenbrenner 1979, Rice et al. 2015, Dickinson et al. 2007).

As direct influence on CAMHS practice within the UK is out of the scope of this study focus is given to how PTs and OTs may support caregivers in this under-resourced area. With campaigns such as Making Every Contact Count (MECC) (Public Health England 2016), clinicians are encouraged to make organisation wide behaviour changes focusing on conversations about mental health and wellbeing. Supporting this further, the NHS five year forward view (NHS 2014) outlines the necessity that people are supported to manage their health and wellbeing to achieve long-term sustainability of not only the healthcare system but the economy. Alongside these campaigns, the NHS standard contract (2019) pushes organisations to ensure that every clinical contact is used as a meaningful interaction to support health and wellbeing. However, the results of this study highlight the 'on the ground' reality for those clinicians and caregivers who responded, showcasing that time and staffing limitations when working with children with CP moving to secondary school does not currently encourage these interactions to take place.

The view of clinicians, that provision of mental health support and the other five topics are outside their 'scope of practice', is an interesting concept to explore considering the use of frameworks such as the ICF in clinical practice (World health organisation 2001). The shift from condition-focused care to FCC and the push for holistic healthcare management directly opposes the presence of these strict boundaries, where healthcare

professionals are unable to be links within a child's ecosystem, assisting families with information or consider how these alternative areas may have an influence on their intervention/management (Bronfenbrenner 1979, World health organisation 2001). It is not possible to consider all aspects of the ICF without the inclusion of the six information topics, for example, the mental health, emotional status and behaviour of the child will have a direct impact on not only the outcomes of therapy intervention but on the child's transition and participation within society.

Contextualising this using Bronfenbrenner's model (1979) for a child with CP, the more links that an ecosystem has, both direct and indirect, the better this is for creating a developmental facilitating environment. The more links present and the more supportive those links available for the child entering a new setting, the more likely it is to facilitate development and alleviate potential anxieties at transition (Bronfenbrenner 1979, Rice et al. 2015, Shelton 2018). Therefore, it is essential that clinicians such as PTs and OTs embrace their potential role as a supplementary link within the child's mesosystem, creating relationships, encouraging the settings to meet conditions which support development and sharing information on topics between each present setting, for example the family and school (Bronfenbrenner 1979). Not only should clinicians strive to use their skills and knowledge to be a supplementary link, they should seek to be a supportive link, through which they can increase the individual child's mesosystem's capacity to facilitate development and the success of transition to secondary school (Bronfenbrenner 1979).

It is therefore important that PTs and OTs consider how they can establish relationships within the child's mesosystem, such as with SENCOs in the school. Clinicians should consider how these relationships and how the provision of information can improve transition between settings and foster an inclusive culture for children with CP. Study findings demonstrate positive support from caregivers and clinicians towards the role of clinicians in information provision at transition to secondary school, using information to not simply facilitate access but to enable children with CP to have an equitable experience of transition to their peers (Booth, T. and Ainscow 2000). Clinicians as supportive links, however, can only be achieved through appropriate training and knowledge. As can be seen in the study results, clinicians felt that if they had more knowledge and training about topics, such as the neglected six, they would be better equipped to provide this support. However, the want for more training and knowledge is in direct competition to the third barrier listed as reasons why clinicians find it hard to

provide this information at transition to secondary school: clinical time and capacity. For many years, increasing pressures on UK NHS clinical capacity has prompted investigation into an array of management tools, including 'lean working' and caseload weighting tools generating ongoing debate between demand and capacity (Kolehmainen et al. 2010, Silvester et al. 2004). As explored by Silvester et al. (2004) NHS organisations often measure activity rather than demand and capacity creating a discrepancy still present in the targets set in today's healthcare system. This discrepancy ultimately affects clinicians, who experience increasing pressures on their clinical time to increase activity in the form of clinical contacts (the number of children they see each day).

As discussed, caregivers of children with CP have increased needs for co-ordination and planning specific to the point of their child's transition and development (Almasri, An and Palisano et al. 2017, Palisano et al. 2009, Reid et al. 2011). These added pressures mean that clinicians lack the time to invest in areas where they feel they require further training or knowledge, leading to the consideration that these areas are outside their 'scope of practice' and it is not possible for them to be able to assist with these information needs. Caregivers response in the current study provided no definite answer as to which professional they felt should provide information on these neglected topics, however highlighted the difficultly caregivers found at getting any professional to provide information. Therefore, from this study the following recommendation is made to assist with the provision of information on neglected information topics.

Recommendations

1) Clinicians and managers working with children with CP at transition to secondary school should consider the benefits of improved partnership working with services such as CAMHS.
2) Joint working arrangements should be considered where services can offer training and support to clinical staff working with children with CP in the provision of these information topics.
3) Training of clinical staff and protected time for regular continuing professional development (CPD) should be embedded to allow staff to explore and expand their knowledge about local services for children with CP at transition to secondary school.

4) Clinicians should be encouraged to develop relationships with education staff, focusing on providing education and information to SENCOs who can then cascade to staff throughout the education environment.

True principles of FCC cannot be achieved without interdisciplinary working and as results demonstrated there are overlaps between the information provision of PTs and OTs at transition to secondary school. The development of community rehabilitation embraces the concept of interdisciplinary working, giving rise to benefits such as pooled knowledge and skills, reducing duplication and more efficient use of resources (Booth, J. and Hewison 2002, Sims, Hewitt and Harris 2015, Smith and Roberts 2005). Interdisciplinary working and role blurring may alleviate clinician concerns regarding information provision being out of their 'scope of practice' whilst providing the opportunity for clinicians to give information in a timely manner (Reid et al. 2011). The concept of professionals using skills from other professionals in their absence is not a new feature in healthcare. For many years, nursing staff have ensured continuity of therapy care, however it is important that clinicians understand what tasks are appropriate to be shared (Sims, Hewitt and Harris 2015). For example, it would be appropriate for PTs and OTs to provide information to caregivers on providing emotional support when guided by knowledge from specialist services however, it would not be appropriate for PTs and OTs to undertake intensive counselling sessions in place of a qualified CAMHS practitioner.

Role blurring and interdisciplinary working in this context can often cause anxiety and conflict if it is not paired with professional role clarity (Sims, Hewitt and Harris 2015). Study findings demonstrate how PTs and OTs are more amenable to role blurring between the two professions when facilitating transition to secondary school. This may be due to the close link between their standards of proficiencies (HCPC 2013, 2013a) or the increased tendency for community therapy teams to be well-balance multidisciplinary teams working towards common goals for children with CP (Sims, Hewitt and Harris 2015, Smith and Roberts 2005, World health organisation 2001).

Findings however suggest that clinicians are more reserved when it comes to the provision of information not directly related to therapy, for example, behavioural support. Despite this, it is a suggestion from this study, through review of literature, FCC principles and the concept of holistic healthcare management, that PTs and OTs assisting in information provision is no more than a continuation of an interdisciplinary approach to become a supportive link in the child's ecosystem (Bronfenbrenner 1979). Viewing clinicians as supportive links within a child's ecosystems and suggesting they assist with

information provision in these areas is no way expecting clinicians to work in an unsafe manner or outside their 'scope of practice' but highlights the potential role for clinicians to increase the continuity of care in the absence of other services by providing advice following direction from specialist services.

For the above recommendations to work, it is necessary for clinicians to understand their role and have sufficient knowledge to underpin how they share information with caregivers (Bronfenbrenner 1979). Bronfenbrenner suggests that individuals, such as PTs and OTs, can be supportive links between settings for development and transition if they encourage the following inter-setting conditions within the child's mesosystem: trust, positive orientation, agreement about goals and shifts in power towards the developing person (Bronfenbrenner 1979, Shelton 2018). These factors are closely linked with the way people perceive and act within settings of the mesosystem. Compatibility of relationships between settings is important in building positive relationships, as it is known that caregivers and family members are influenced by not only their beliefs but the context in which they receive healthcare (Almasri, An and Palisano 2017, Law et al. 2003). Due to the influence of caregivers' perceptions it is therefore important for clinicians to consider how they present information to caregivers and if the style of information provision is acceptable (Gulmans et al. 2009, Lagosky, Barlett and Shaw 2016.)

Within this study clinicians highlighted information provision as an integral part of their current clinical practice. Caregivers echoed literature, stating the benefits from verbal interactions and particularly valued the opportunity to ask questions (Reid et al 2011). The importance of communication in healthcare is not a new concept. As explored by Bronfenbrenner (1979), communication happens between settings in a variety of ways and is more likely to positively promote development if it is an easy two-way process. Communication between healthcare professionals and patients has been shown to be key in developing collaborative decision-making and when working with children with CP, vital in bridging the gap between all services placed within the child's ecosystem (Almasri, An and Palisano 2017, Bronfenbrenner 1979, Mahon and Cusack 2002, Politi and Street 2011).

Study findings show the value placed on verbal interaction, showing the benefit caregivers experience when they have personal interactions with clinicians. Bronfenbrenner (1979) explained personal communication as a key feature of successful development and information sharing. His work explained how face-to-face

communication can allow individuals to interpret non-verbal communication however more importantly provides them with the opportunity to ask for more information (Bronfenbrenner 1979). This is a key concept in developing inter-setting knowledge to aid smooth transition (Bronfenbrenner 1979). Caregivers are often viewed as 'experts' about their child, whilst empowering and reflective of FCC principles, this view does not contemplate the level of knowledge required to understand the intricacies in the management of CP and the level of communication and time required to build and maintain relationships between all settings within the child's ecosystem. The findings of this study support research that caregivers look to healthcare professionals for guidance, and value the resources provided to them in supporting their decisions (Almasri, An and Palisano 2017, Lagosky, Barlett and Shaw 2016, Mahon and Cusack 2002, Palisano et al. 2009).

Alongside this, caregivers demonstrated their preference for information to be written down, providing a document that can be used within inter-setting communication. Having a report outlining their child's needs assists them in preparation for supporting their child through transition and provides them with inter-setting knowledge (Bronfenbrenner 1979). Bronfenbrenner supports the sharing of information in this way suggesting that members of both settings, in this case the family and school should be provided with '*information, advice and experience relevant to the impending transition*' (Bronfenbrenner 1979:217). With this he suggests that people are more likely to respond appropriately to each other, have more positive experiences and achieve greater reciprocity in the microsystem of the new setting (Bronfenbrenner 1979, Shelton 2018). Information provided to families in this manner can positively affect how the child is prepared for transition, with better understanding of the new setting and skills required to adapt (Bronfenbrenner 1979). However, this effect is determined by how accurate the communication is and how often it is updated, therefore it is recommended from study findings that clinicians follow several key elements, suggested by caregivers, to achieve successful inter-setting knowledge sharing and communication.

Recommendations

1) Information should be simple to understand
2) Information should be specific to the child's needs at transition
3) Information should be recorded in a clear manner
4) Information should be accessible to caregivers at all times, providing a point of reference.

5) Clinicians should allow time for discussions with caregivers of children with CP during the transition to secondary school or should offer regular opportunities for caregivers to ask questions.

The study has described clinician's current attempts to meet the information needs of caregivers, however it was highlighted that clinicians also require direction and support, provided in the form of NICE guidelines (NICE 2017). Study findings demonstrated mixed experience with the use of tools such as 'patient folders' in clinical practice. These experiences highlight the importance and clinical implications of knowledge translation. Knowledge translation is a widely debated concept yet is most commonly defined as a 'dynamic' and 'iterative' process involving key features such as dissemination and exchange of knowledge aiming to achieve more effective healthcare systems (Khoddam et al. 2014). It is expected by not only caregivers, but by regulatory bodies, that PTs and OTs are able to assist in the process of knowledge translation into clinical practice (HCPC 2013, 2013a). The standards underpin the expectation of clinicians to be able to gather knowledge, from research or non-research sources, and transfer this into clinical practice for the benefit of patients and services. As explored within literature, the concept of knowledge translation was developed to provide professionals with an 'easy to understand body of knowledge' which can be directly implemented (Khoddam et al. 2014).

However, it is clear from study findings that guidelines for the management of children with CP have not yet been implemented consistently into clinical practice. It is evident that clinicians lack both time and support to engage in this dynamic process, to be able to try out and evaluate the effectiveness of guideline suggestions, such as 'patient folders' (NICE 2017). Study findings highlight that there is little evidence in clinical practice as to the effectiveness of using such resources to support the transition to secondary school. These findings may be due to the fact that at the time of the study the guidelines were relatively new into clinical practice however despite this both clinicians and caregivers viewed the use of such resources as positive. Therefore, the following recommendations are made to overcome the challenges of knowledge translation of clinical guidelines.

Recommendations

1) Clinicians need to be provided with time to access evidence-based information and develop understanding of clinical guidelines about the management of children with CP.

2) Managers in clinical practice need to ensure they have an awareness of up to date clinical guidelines for the management of children with CP and have strategic plans of how evidence-based suggestions can be integrated into their clinical services
3) Guideline committees should ensure that they have robust implementation and dissemination plans to ensure circulation of new guidelines are widely publicised and shared with appropriate clinicians.

5.3 Gaps in the nature and means of information provision to caregivers of children with CP at transition

As explored, clinicians highlighted issues in the translation of clinical guidelines into practice. Clinicians highlighted 15 barriers to providing information at transition to secondary school categorised into three areas. Comparison between clinician's approach and caregiver's needs demonstrated a 'mismatch in priorities'. The mismatch is shown throughout literature outside of the UK, with differences in patient and clinician priorities being attributed as a reason behind poorly established FCC (Jeglinksy, Autti-Rm and Brogren Carlberg 2012, Seibes et al. 2012). Notable for all barriers, clinician's interpretations of the most impactful barrier differed from caregivers. For example, for healthcare provision, clinicians indicated resources as the biggest barrier, yet caregivers highlighted clinician's limited time as most impactful. Prior to this study it was unknown if mismatches demonstrated in the above literature were present within UK clinical practice.

A key theme supported in study findings is that discrepancy between clinician's time and caregivers needs at transition is a long-standing and continuing problem (Almasri, An and Palisano et al. 2017, Palisano et al. 2009, Reid et al. 2011). The study recommendation of interdisciplinary working may provide a solution to providing information on neglected information topics, however it is unlikely to fully alleviate the time pressures on clinicians and meet the needs of caregivers specifically at the point of transition to secondary school, making it necessary to consider other avenues of practice. To consider how clinicians can may use their time effectively when choosing what information to provide it may be useful to consider the concept of 'developmental trajectory', defined as development occurring because of experiences connected over time (Bronfenbrenner 1979). Bronfenbrenner (1979) suggests that the best predictor for future behaviour, in the context of this study how a child copes with transition, is to review past behaviour.

The concept discusses the importance of support being present in both the new setting, secondary school, and the old setting, primary school. Support within these settings is viewed as a balance, with too little support from either setting the child may not be able to sufficiently adapt and the development opportunity lost. Yet, with too much support, the child will not have to adapt to the setting and once more the development opportunity lost (Bronfenbrenner 1979, Shelton 2018). This is a challenging concept for all working with children with CP, however for PTs and OTs it directs them to review the child's developmental status and establish how this may project into the next setting (Bronfenbrenner 1979, Shelton 2018). Therefore, this study recommends for PTs and OTs to consider the following statements during transition planning to ensure they provide meaningful information to caregivers and settings aiming for successful developmentally facilitating transitions to secondary school.

Recommendations

1) PTs and OTs should consider if there is enough support in primary school and secondary school to keep the child with CP's developmental trajectory in motion.
2) PTs and OTs should consider if there is enough challenge in primary and secondary school to stimulate and strengthen the child with CP's developmental trajectory.

The above recommendations are not without consideration of the role of PTs and OTs in information provision at the specific point of transition to secondary school. Education-led research highlights an established role for healthcare professionals however there is a continuing debate between health and disability studies as to the benefit of this role and interventions (McLaughlin 2013, Rice et al. 2015). Whilst attempting to help the child, aiming to increase the child's independence and participation, there is a contrasting argument as to whether interventions can emphasise the child's difference, medicalising their identity and experiences as they develop alongside their peers (McLaughlin 2013).

Davis (2013) highlights the tendency of professionals to fail to consider the views of the child and family, with professionals having varied approaches. Coupled with the above recommendations to ensure a balance of support is created, this demonstrates the importance of models such as Bronfenbrenner's ecological systems framework and holistic frameworks such as the ICF (Bronfenbrenner 1979, World Health Organisation 2001). These are essential for ensuring clinicians consider all factors associated with the child's ecosystem yet, intentionally place the developing child at the centre of the model/framework to ensure clinicians focus on their needs and views. The use of these

models is specifically important at transition to secondary school when working to increase independence of the child as they reach adolescence and can be a positive tool to ensure all influencing factors are considered in the child's management (Bronfenbrenner 1979, Rice et al. 2015).

Clinicians recorded organisational and structural barriers which impact on their ability to provide information at transition, such as increased number of school staff involved with the child at secondary school or concerns regarding the volume of information shared with caregivers. Considering barriers such as these, Davis (2013) discusses the emphasis that is placed on structural barriers however challenges the personal and cultural views of organisations and institutions. Not taking away from the necessity to address these structural barriers in clinical practice, Davis (2013) promotes the notion of fluid change in the approach to disability and childhood studies, further encouraging professionals, as in the ecological systems model, to consider that children's lives will be different depending on the context in which they live (Bronfenbrenner 1979).

Mismatch in barriers was also viewed in study findings, for example caregivers were not concerned by the level of information but were more concerned by the lack of knowledge around their specific needs as their child transitions to secondary school. It is particularly important for PTs and OTs to consider each child's individual ecosystem, the settings and the roles present within it as this will have an influence on the capacity of the mesosystem to provide a developmentally facilitating environment (Bronfenbrenner 1979). However, it is equally important that PTs and OTs acknowledge that there will be times that children with CP may not wish to be defined as 'different' from their peers or 'disabled' (Davis 2013). This is an important factor to consider in the transition to secondary school, as if the child does not feel that they are encountering any barriers, there may be a reduced need for intervention from PTs and OTs. This once more demonstrates the importance of communication and development of effective links which embody trust, agreement in goal setting and shifts in power towards the developing person (Bronfenbrenner 1979, Shelton 2018). Considering the above the following recommendations are made as to how services should try to overcome structural barriers.

Recommendations

1) Management in both healthcare and education should seek to provide protected time for staff involved in transition of children with CP to secondary school to allow time for generation of information, education and support.

2) Clinicians should aim to utilise their communication skills to generate positive links with key people within the child's mesosystem, including education staff.
3) Clinicians should strive to use frameworks such as ICF and ecological systems model to ensure they consider all influencing factors at the point of a child with CP's transition.
4) Clinicians should ensure that they maintain the child at the centre of care and ensure their views are listened to and responded to appropriately, even if that be reduction in intervention.

5.4 Caregiver-informed strategies for future information provision and caregiver experiences of good practice.

As the above objective was to collect caregiver's experiences and potential strategies for future information provision it is necessary to review the response rate of the caregiver questionnaire and the influence this may have had on achieving this study objective. As described in chapter 3, methodology and methods, the study was carried out as a 'nation-wide' survey throughout the UK. Despite the seemingly small sample size (Cg1 [n=7] and Cg2 [n=2]) the response rate was in line with expected online survey response rates (Braithwaite et al. 2003). Braithwaite et al. 2003 suggests that online survey response rates commence at approximately 30% and with the use of reminders may increase to 52.40%. As can be seen in this study, from this initial sample of caregivers there was a 50% response rate. Reminder emails were requested to improve the response however timing and frequency of these were controlled by the gatekeepers (Cunningham et al. 2015). Despite being approximately 11% lower than the average paper survey response rate, the ease of implementation and ability to perform large-scale national survey, alongside the elimination of costs such as stationery and postage, made it the most suitable method of choice (Baruch 1999, Braithwaite et al. 2003).

As it was not possible to undertake a power calculation due to the unknown number of caregivers of children with CP living in the UK, the sampling method undertaken intended to capture participants with relevant experience in the topic of study (Patton 2002). Due to this approach, it was not an intention of the study to generate generalisable findings to the wider population of caregivers of children with CP or caregivers of children with other disabilities, therefore findings are presented in the context of this study focusing specifically on PTs, OTs and caregivers of children with CP at the point of transition to secondary school. Literature widely states salience as a main factor for reduced participation in online surveys which could give reason to the attrition of potential

participants in the caregiver's questionnaire (Baruch 1999, Cook, Heath and Thompson 2000, Fan and Yan 2010). Sheehan (2001) highlights salience as having the greatest impact on response rate, greater than any other factor of survey research including research design. The findings of the current study reflect those within literature and therefore strategies for future information provision and solutions to overcome barriers will be discussed in light both participant groups.

Study findings showed caregivers viewed information provision at transition as 'essential' reinforcing the necessity of FCC principles (Raina et al. 2005). However, the experiences of caregivers in this study outlined a concern that information provision does not always coincide with the developmental milestones of their children with CP. Raising an important concept about the role of support throughout education, considering whether each year within education should be classed as a 'transition' as children move to new teachers and classrooms. This related closely to the previously discussed concept of developmental trajectory and the view of caregivers within this study supports the role of clinicians in using the child's developmental status to guide the information provided at transition (Bronfenbrenner 1979, Shelton 2018).

Caregivers reinforced the previously discussed importance of communication and links between settings. Caregivers presented experiences where for example, in relation to information about their child's social interaction, clinicians had assumed that education staff would provide this information. Caregivers acknowledge the challenges surrounding these topics and supported the role of clinicians using interdisciplinary working to build these supportive links within their child's mesosystem. Bronfenbrenner (1979) highlights the important of these links however suggests a 'closed activity network' where shared experiences within a variety of settings can aid development and gradually increase power to the developing individual (Bronfenbrenner 1979). Undertaking activities in more than one setting can increase development potential and thus adaption in transition to new settings. For example, if activities to assist a child with CP to transition to secondary school are undertaken, at home, primary school, secondary school and therapy sessions, this is more likely to be developmentally beneficial than if activities were undertaken solely in one setting for example, practising mobility solely in therapy sessions. Not only can this have benefits to the child but families with positive activity networks potentially have more beneficial systems overall (Bronfenbrenner 1979, Shelton 2018). Such improvements in family functioning has shown benefits to child

wellbeing throughout research (Almasri et al. 2011, Kruijsen-Terpestra et al. 2014, Law et al. 2003, Palisano et al. 2009, Raina et al. 2005).

Clinicians should therefore consider how they can be involved in the 'closed activity network'. Previous research has suggested that clinicians should adopt a personal mentoring approach or create times where caregivers have a place for personal communication however, from this study, this does not appear to be an approach currently adopted in UK clinical practice (Knis-Matthews et al. 2011, Kruijsen-Terpestra et al. 2014). As previously discussed and recommended, both caregivers and clinicians agreed that protected time for staff involved in transition would be beneficial however, there continued to be a mismatch in the perception of barriers to information provision. Clinicians demonstrated concern about the amount of information given to caregivers however this was not a concern for caregivers. This continued mismatch highlights the importance of developing a partnership approach not only in management of the child with CP but in the approach to interventions, service design and research (Buran et al. 2009).

5.5 Areas for future research

Study findings demonstrate a mismatch and lack of current partnership between AHPs (PTs and OTs) and caregivers of children of CP at transition to secondary school. A strength of this study was the possibility to gather valuable information about how PTs and OTs currently provide information to caregivers of children with CP at the transition to secondary school whilst gathering the current experiences of caregivers. This has provided a foundation of understanding and a platform for the following recommendations for areas of future research.

Recommendations

1) There is a need for further qualitative research focusing on the child with CP at the centre of the care exploring their views and experiences. In order to achieve this, alternative methodologies, such as focus groups, interviews or creative methodologies engaging to children would need to be used.
2) Further research is required involving both caregivers of children with CP and clinicians in the planning and development of suitable approaches or resources to overcome barriers to information provision at transition to secondary school.

3) Consideration should be given to further exploring the perspectives of children with CP and caregivers' perspectives of looking after a child with CP using an exploratory rather than descriptive approach.
4) Research into the relationship between health and education staff may be beneficial to establish the role of clinicians in the education of staff and involvement in transition planning for children with CP as they move to secondary school.
5) Research into the influence of specialist assessment tools for CP, such as the Gross motor function measure, and their effects on information provision would be beneficial to further understand clinician's preferences, with comparison between professions explored.
6) Research investigating the use of suggested solutions such as 'buddy systems' or 'closed activity networks' would be beneficial in exploring the effect of these on children with CP during the transition to secondary school.

6 Limitations of the current study

6.1 Caregivers group

A limitation to the study is the number of caregivers who completed both the first-round questionnaire and the second-round questionnaire. As previously explored the response rate from those participants who accessed the survey was acceptable, however the attrition of participants from those who accessed the initial information of the study needs to be acknowledged. The study's use of gatekeepers, although providing a level of safeguard for participants, may have unintentionally missed potential participants as the study method was reliant on participants receiving the initial invitation and thus potentially being a member of the gatekeeper organisation. In contrast to this the number of times the survey was accessed demonstrates the successful distribution of the initial invitation through the chosen gatekeepers. Furthermore, it is noted that the study was reliant on participants actively engaging with the request from the gatekeeper. The attrition of potential participants may have been related to the information provided. The detailed and robust information may have stopped participants continuing with the study.

When considering the characteristics of the caregivers' group it is necessary to note that the gender of participants may be considered a limitation to the current study. As all caregivers who completed the survey were female this may mean that the findings of the survey are biased towards a female perspective.

6.2 Online Survey methodology

As previously discussed, the use of online survey methodology and gatekeepers created a reliance on active engagement of participants. The use of an online questionnaire may have ruled out participants who do not have access to the internet or do not feel confident in completing online questionnaires, however in today's society it is common for the majority of households to have internet access and it is not unrealistic to expect that many caregivers of children who will be at the age of transition to secondary school will be proficient in the use of the internet.

Despite this, it is necessary to consider that caregivers of children with CP may have found the online methodology inappropriate or inaccessible as the process of an online survey may have been unfamiliar to them. In this sense the methodology could be considered as more suited to professionals who frequently complete such tools as part of their roles.

The nature of the online methodology used within this study could also have provided challenges which may be considered a limitation to the study. When using an online methodology, it is not possible to know the additional support requirements of every participant. Potential participants in both groups, clinicians and caregivers, may have had specific learning requirements which were not able to be accommodated in the fixed survey format.

It is realistic to expect that all professionals working within todays health care system would have the appropriate literacy and information technology skills to be able to understand the processes associated with taking part in an online research project however this may not have been the case for non-professionals completing the questionnaires. Literacy levels vary greatly throughout the United Kingdom and the use of an online methodology may have precluded some caregivers from taking part in the study. Although health literacy was considered within the questionnaire design, through use of the Fogg index (Matthews, Fox and Hunn 2009), this approach was not applied to the introductory information given to potential participants in the form of the patient information sheet, screening process and embedded consent form.

This could be considered a limitation of the study as participants may have found the information too long or difficult to understand, meaning they did not progress through to access the survey questions. Opportunity was provided for participants to ask the researcher questions about the study however the online nature of the questionnaire

meant that this was not immediate and support to complete the questionnaire relied on participants contacting the researcher. Therefore, alternative methods which would make research projects accessible to this cohort have been considered in the future research section.

6.3 Questionnaire Design

Despite careful consideration of the questionnaire design ensuring face and content validity of the questions and the use of the Fogg index in a bid to make the questions understandable and accessible to all participants, the lack of caregiver or child involvement in the design of the questionnaire could be considered a limitation to the study.

Only an expert panel was used to review the content and usability of both questionnaires. As outlined in Phillips et al (2019) the panel review demonstrated that the research design and questionnaires were addressing a question relevant to children, young people, their families and professionals however the lack of caregiver and children engagement in the research design is something that could have been improved given increased time and resources.

A challenge to the researcher for the inclusion of caregivers/children within the questionnaire design was access. As outlined within the ethical application of the survey, no recruitment or work for the project was completed through the researcher's role as a clinician working with children with CP. Alongside this, the researcher's NHS trust did not have known patient and public involvement volunteers available for paediatric research making involvement challenging. The involvement of children/caregivers in the questionnaire design could have improved the accessibility of the information presented.

Since completing this project the researcher has highlighted the lack of opportunity for patient and public involvement (PPI) in children and young peoples' research at the researchers NHS trust and has since started working with the trust engagement officer to establish a network for children and young people's PPI moving forward. This will enable more input into future research for this cohort of children and caregivers.

7 Conclusion

This study has highlighted the lack of understanding about the role of UK clinicians in information provision for children with CP as they transition to secondary school. Describing the current information needs of caregivers and current clinical practice the study has shown important mismatches in priorities between clinicians and caregivers. This study has provided recommendations to review UK current clinical practice. Recommendations are provided on partnership working, training needs, presentation of information and use of clinical guidelines. The role of PTs and OTs in supporting children with CP at the transition to secondary school are also considered.

This study highlighted existing barriers to the successful provision of information at transition to secondary school. Recommendations are provided for ways to overcome structural and organisational barriers including areas for future research. Importantly the study lists the importance of successful communication and information provision and demonstrates ways which these can be improved in UK clinical practice to support caregivers of children with CP at the transition to secondary school.

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9 Appendix

9.1 Appendix 1 - NICE guidelines (2017) recommendations

11.6 Recommendations

35. **Ensure that information and support focuses as much on the functional abilities of the child or young person with cerebral palsy as on any functional impairment.**

36. **Provide clear, timely and up-to-date information to parents or carers on the following topics:**
    - diagnosis (see section 6.7)
    - aetiology (see section 5.6)
    - prognosis (see section 10.7)
    - expected developmental progress
    - comorbidities
    - availability of specialist equipment
    - resources available and access to financial, respite, social care and other support for children and young people and their parents, carers and siblings (see also recommendations 147 and 152)
    - educational placement (including specialist preschool and early years settings)
    - transition (see section 29.6).

37. **Ensure that clear information about the 'patient pathway' is shared with the child or young person and their parents or carers (for example, by providing them with copies of correspondence). Follow the principles in the recommendations about communication, information and shared decision-making in the NICE guideline on patient experience in adult NHS services.**

38. **Provide information to the child or young person with cerebral palsy, and their parents or carers, on an ongoing basis. Adapt the communication methods and information resources to take account of the needs and understanding of the child or young person and their parents or carers. For example, think about using 1 or more of the following:**
    - oral explanations
    - written information and leaflets
    - mobile technology, including apps
    - augmentative and alternative communication systems (see section 16.7).

39. **Work with the child or young person and their parents or carers to develop and maintain a personal 'folder' in their preferred format (electronic or otherwise) containing relevant information that can be shared with their extended family and friends and used in health, social care, educational and transition settings. Information could include:**
    - early history
    - motor subtype and limb involvement
    - functional abilities
    - interventions
    - medication
    - comorbidities
    - preferred methods of communication
    - any specialist equipment that is used or needed
    - care plans
    - emergency contact details.

40. **Ensure that the child or young person and their parents or carers are provided with information, by a professional with appropriate expertise, about the following topics relevant to them that is tailored to their individual needs:**
    - menstruation
    - fertility and contraception
    - sex and sexuality
    - parenting.

41. **Provide information to the child or young person and their parents or carers, and to all relevant teams around them, about the local and regional services available (for example, sporting clubs, respite care and specialist schools) for children and young people with cerebral palsy, and how to access them.**

42. **Provide information about local support and advocacy groups to the child or young person and their parents or carers.**

9.2 Appendix 2 – First-round questionnaires

Clinician questionnaire – Cl1

Introduction

Thank you for considering to undertake this survey.

Please review the following inclusion criteria.

If you meet these you will be directed to the study information sheet.

If you have any questions regarding the study please do not hesitate to contact me.

Yours Sincerely,

Amy Howells (southal8@uni.coventry.ac.uk) - Post Graduate Research Student – Coventry University

Dr Tanya Rihtman ab4236@coventry.ac.uk - Supervisor

Inclusion criteria

- I am a Health care professions council (HCPC) registered physiotherapist or occupational therapist
  Yes/No
- I work in the United Kingdom
  Yes/No
- I am a therapist working with children with a diagnosis of cerebral palsy as they transition from primary to secondary school.
  Yes/No
- I have at least 18 months experience working with caregivers who have children with a diagnosis of cerebral palsy
  Yes/No

Clinician information sheet

Consent form

Demographic Information

1) **Are you a physiotherapist or occupational therapist?**
   - Physiotherapist
   - Occupational therapist
2) **How long have you worked with children with cerebral palsy?**
   - 18 months – 2 years
   - More than 2 years but less than 5
   - More than 5 years but less than 10 years
   - More than 10 years
3) **What grade therapist are you?**
   - Band 5
   - Band 6
   - Band 7
   - Band 8
   - Band 9/Consultant
   - Private sector
   - Other
4) **Which area of the UK do you practice?**

	Please state regional area
England	
Wales	
Scotland	
Northern Ireland	

5) **What best describes the functional ability of the children on your caseload? Please select all that apply**
   - GMFM 1, GMFM 2, GMFM 3, GMFM 4, GMFM 5
6) **What best describes where you provide your therapy intervention? Please select all that apply**
   - School – mainstream
   - School – MLD
   - School – SLD
   - School – PMLD
   - Hospital
   - Doctors Surgery
   - Medical/Health Centre
   - Children's/Specialist Centre
   - Other
   - If you selected other, please specify

Questions designed for this study

7) **NICE guidelines (2017) suggest caregivers should be provided with information about the following topics which are appropriate to therapists.**
   Please select the topics you provide information about;
   - Diagnosis
   - Prognosis
   - Expected developmental progress
   - Co-morbidities
   - Availability of specialist equipment
   - Access to financial support
   - Access to respite care
   - Access to social care
   - Educational placement (including specialist settings)
   - None of the above
   - Other
   - If you selected other, please specify

8) **If you provide any of the above information, how do you do this?**
   - Verbal (oral explanations)
   - Written information
   - Leaflets
   - Mobile technology
   - Augmentative and alternative communication systems
   - Other
   - If you selected other, please specify
9) **Guidelines recommend creating a 'Patient Folder'.**

a) **What do you understand this to mean?**
   Free text box

b) **Is this something you have done in practise?**
   - Yes/NO
   - If Yes – **what was your experience of this (positive/negative) and how do you do this?**
     Free text box
   - If No – **why was this? (barriers)**
     Free text box

10) **Do you currently provide information for children with cerebral palsy as they move from primary to secondary school? (I,e. to child, caregivers, school staff).**
    i. Yes/ No
    ii. If yes, continued
    iii. If no, please move to question 13

11) **Do you provide information on any of the following therapy specific topics?**

Information on;	
Transfers (i.e. moving from chair to floor)	
Toileting	
Washing	
Dressing	
Exercises (Physiotherapy)	
Exercises (Occupational Therapy)	
Walking including use of aids i.e frame/sticks	
Stairs	
Access to leisure activities (including sports clubs)	
Access to buildings/environment	
Aids to assist with eating/drinking	
Aids to assist with work, i.e. pens etc	
Use of splints or orthoses (i.e insoles)	
Social Interaction	
Self-organisation skills – packing school bag, homework, planning.	
Female menstruation support	
Mental Health Support	
Behavioural Support	
Emotional Support	
Other (please state)	

a) **If you selected other, please specify:**

b) If you feel that you would like to explain further or add any further information, please enter it here:

Free text box

12) **How do you provide this information?**

- Leaflet/handout with written information
- Leaflet/handout with Pictures
- Verbal information
- App
- Website
- Other
- If you selected other, please specify

13) **In your experience or in your understanding, what might the positives of providing this information be?**

i. Free text

14) **In your experience, what are the barriers to providing information to caregivers of a child with cerebral palsy, who is moving from primary to secondary school?**

i. Free text

15) **What do you feel would help to overcome the above barriers and support you to provide information from caregivers of a child with cerebral palsy, who is moving from primary to secondary school?**

i. Free text

16) **Is there anything else you would like to add?**

i. Free text

Email Submission

17) **Would you like to submit your email address?**

Yes.

No. I understand that I will not be able to withdraw my responses.

Email Submission

Please submit your email address; you will have 2 weeks from submitting the questionnaire to withdraw your responses should you change you mind about participation.

Phase 2 study

Once this questionnaire has been completed, the researcher plans to share the results with participants as a phase 2 of the study, to make sure participants have the opportunity to comment on the results of phase 1. Do you consent to be contacted directly by the researcher to take part in the second questionnaire?

Yes. I consent to the researcher contacting me for phase 2 of the study.

No, I do not wish to be contacted.

Email Submission

Please submit your email address. Please note this will mean your responses are no longer anonymous.

Submission

Please submit your questionnaire.

Thank you

Content removed on data protection grounds

Caregiver questionnaire – Cg1

Introduction

Thank you for considering to undertake this survey.
Please review the following inclusion criteria.
If you meet these you will be directed to the study information sheet.
If you have any questions regarding the study please do not hesitate to contact me.
Amy Howells (southal8@uni.coventry.ac.uk) –
Post Graduate Research Student – Coventry University
Dr Tanya Rihtman ab4236@coventry.ac.uk - Supervisor

Inclusion criteria checklist

- I am a caregiver for a child who has a primary diagnosis of cerebral palsy

  Yes/No
- I am the caregiver for a child with a diagnosis of cerebral palsy who is due to transition from primary to secondary school education in September 2018 or has transitioned within the last two years (2016-2017 or 2017-2018).

  Yes/No
- I am the caregiver of a child with cerebral palsy living in the United Kingdom when the child moved or is due to move from primary to secondary school.

  Yes/No
- I am the caregiver of a child who has received wither physiotherapy and/or occupational therapy treatment during their transition from primary to secondary school.

  Yes/No
- Does the child you care for have any of the following diagnosis? **Selection list**
  - Chronic illness (i.e. Cancer, Rheumatoid arthritis, Asthma)
  - Syndrome (i.e. Downs Syndrome, Emmauel Syndrome)
  - Autistic Spectrum Disorder
  - Attention deficit/hyperactivity disorder
  - Developmental co-ordination disorder
  - Acquired traumatic brain injury before the age of three
  - Acquired brain injury after the age of three
  - None of the above.

Caregiver information sheet

Consent form

Demographic information

1) **Please select one of the following which best describes your relationship to the child;**
   - Mother
   - Father
   - Grandmother
   - Grandfather
   - Carer
   - Other
   - If you selected other, please specify:
2) **Which area of the UK do you live in?**

	Please state regional area
England	
Wales	
Scotland	
Northern Ireland	

3) **When is your child due to move or did your child move from primary to secondary school education?**
   - 2018
   - 2017
   - 2016

4) **What type of school does your child attend?**
    - Mainstream
    - Moderate learning disabilities school
    - Severe learning disabilities
    - Profound and Multiple learning disabilities
    - Home Schooled
    - Boarding School
    - Private schools (day student)
    - Private school (residental student)
    - Other
    - If you selected other, please specify:

5) **How does your child communicate with you and others?**
    - Verbal
    - non-verbal i.e. sign language/Makaton
    - assisted communication devices i.e. computer programmes
    - eye-gaze
    - Other
    - If you selected other, please specify:

6) **Please select any of the following words which best describe your child's cerebral palsy**
    - Hemiplegic
    - Hemiplegic (one side of body involved)
    - Diplegic (legs involved)
    - Quadriplegic (all four limbs involved)
    - Tetraplegic (three limbs involved)
    - Monoplegic (one limb involved)
    - Spastic
    - Dystonic
    - Dyspraxic
    - Athetoid
    - Ataxic
    - Mixed
    - Hypertonic (high toned)
    - Hypotonic (low toned)
    - I am not sure
    - Other
    - If you selected other: please specify:

7) **When discussing your child's cerebral palsy diagnosis has anyone ever mentioned their Gross motor function measure classification to you? If so, please select one of the following. If you do not know, please select 'I don't know'. The descriptors below may help you choose an option.**
    - GMFM 1
    - GMFM 2
    - GMFM 3
    - GMFM 4
    - GMFM 5
    - I don't know

Image of GMFM

8) **Please select from the following which best describes your child's functional abilities for each of the following areas;**

Ability	Completely Dependent – child cannot assist in the activity	Constant physical support while child performs activity	Occasional physical support while child performs activity	Supervision only – needs adult attention for health and safety but no physical support	Completely Independent – chid performs the activity alone with or without aids
Rolling over					
Transferring from bed to chair/out of bed					
Washing					
Dressing					
Toileting					
Walking					
Stairs					
Eating/Drinking					
Social Interaction					
Female menstruation support					
Use of aids/splints					
Access to buildings/environment					
Self-organisation skills – packing school bag, homework					
Access to leisure (including sports clubs)					

9) **Which therapy has your child received? Please select all that apply**
Physiotherapy, Occupational Therapy

10) **How often does your child receive therapy from a qualified therapist?**

	Once a week	Twice a week	More than twice a week	Once every two weeks	Once a month	Other	If you selected other, please state
Physiotherapy							
Occupational therapy							

11) **Where does your child usually receive therapy intervention? Select all that apply**

	Home	School	Medical/health centre	Doctors surgery	Hospital	Other	If you selected other, please state
Physiotherapy							
Occupational therapy							

12) **Does your child have an approved EHCP (Education and Health Care plan)?**
Yes/No

13) **How many hours physiotherapy does your child receive as part of their EHCP?**

14) **How many hours occupational therapy does your child receive as part of their EHCP?**

Questions designed for this study

Note: The following questions have been designed for this study

15) **Has/Did your physiotherapist or occupational therapist give you information to help with your child's transition from primary to secondary school?**
    i. Yes/No
    ii. If yes
    iii. If no – Participant routed to question 19.
16) **If Yes, What information did they give you?**
    i. Free Text box
    b. **Did you find this helpful?**
        i. Yes/No
        ii. **If no, Why was this not helpful?**
        Free Text box
    c. **Would you have liked more information?**
        i. Yes/No
        ii. **If Yes, what would you have liked more information about?**
        Free text box
17) **How did your Therapist give you information? (for example leaflets, verbal, other)**
    i. Free Text box
18) **Was this format of information helpful?**
    i. Yes/No
    b. **If Yes, What was good about the format of the information you received?**
        i. Free text box
    c. **What could have been improved?**
        i. Free text box
19) **Has/Does your therapist copy you into information that they provide to school?** Yes/No
    a) **Was/is this helpful?**
    b) **If no, why was/is this not helpful?**

20) **What information would you like to/liked to receive during your child's move from primary to secondary school? Please select all that apply**

Information on;	
Transfers (for example moving from chair to floor)	
Toileting	
Washing	
Dressing	
Exercises (Physiotherapy)	
Exercises (Occupational Therapy)	
Walking including use of aids i.e frame/sticks	
Stairs	
Access to leisure activities (including sports clubs)	
Access to buildings/environment	
Aids to assist with eating/drinking	
Aids to assist with work, i.e. pens etc	
Use of splints or orthoses (i.e insoles)	
Social Interaction	
Self-organisation skills – packing school bag, homework, planning.	
Female menstruation support	
Mental Health support	
Behavioural support	
Emotional support	
Other (Please state)	

21) **How would you like to receive information to help your child during the move from primary to secondary school? Please choose all that apply**
    i. Leaflet/handout with written information
    ii. Leaflet/handout with Pictures
    iii. Verbal information
    iv. App
    v. Website
    vi. Other

a) **Why do you think the above choice would help?**
    vii. Free text

22) **Is there anything else you would like to add?**
    i. Free text

23) **Would you like to submit your email address?**
    Yes
    No. I understand that I will not be able to withdraw my responses

Email submission

Please submit your email address; you will have 2 weeks from submitting the questionnaire to withdraw your responses should you change you mind about participation

Phase 2 study

Once this questionnaire has been completed, the research plans to share the results with participants as phase 2 of the study.

24) Do you consent to be contacted directly by the researcher to take part in the second questionnaire?
    Yes. I consent to the researcher contacting me for phase 2 of the study.
    No. I do not wish to be contacted.

Email Submission

Please supply your contact email address. Please note this will mean your responses are no longer anonymous.

Submission.

Please submit your questionnaire.

Thank you

Thank you for taking part in this study.
If you have any questions please contact the researcher on Southal8@coventry.ac.uk
Thank you once again,
Amy Howells
Post Graduate Researcher – Coventry University

9.3 Appendix 3 – Second-round questionnaires

Clinician questionnaire – Cl2

Introduction

Thank you for consenting to receive the second questionnaire in relation to the study you participated in earlier this year.

Study Title: Physiotherapy and Occupational therapy information needs of caregivers of children with cerebral palsy, living in the United Kingdom, during the transition from primary to secondary school.

The results of the first questionnaire have now been collated. We would be very grateful for your comments on the results from the first phase of the study.

If you have any questions regarding the study please do not hesitate to contact me.

Yours Sincerely,
Content removed on data protection grounds

Demographic Information

1) **Are you a physiotherapist or occupational therapist?**
   Physiotherapist
   Occupational therapist
2) **How long have you worked with children with a diagnosis of cerebral palsy?**
   18 months – 2 years
   More than 2 years but less than 5 years
   More than 5 years but less than 10 years
   More than 10 years
3) **What grade therapist are you?**
   Band 5
   Band 6
   Band 7
   Band 8
   Band 9/consultant
   Private sector
   Locum
4) **Which are of the United Kingdom do you practice**
   England
   Scotland
   Wales
   Northern Ireland

Use of 'patient folders'

In our previous questionnaire we asked about the use of a 'patient folder' in clinical practice. 75% of clinicians (Physiotherapists/Occupational therapists) who responded had not or did not use this in their practice.
They outlined the following barriers of using a 'patient folder'

5) **For the following 10 barriers, please rank them by what you would consider the most significant (Rank 1) to the least significant barrier (Rank 10). (N.B. Please only select each rank once. If you do not consider it a barrier please leave the question blank.)**

Barrier	Rank
This is not something that is done/has been implemented in my department/trust.	
I am unsure about whose responsibility it is to complete/lead on this and am I unsure if this is part of my role.	
I was unaware of a 'patient folder' or do not know what it is.	
I do not have enough time to use a 'patient folder'.	
Communication between services is not good enough to provide a 'patient folder'.	
Multi-disciplinary team working between services is not good enough to provide a 'patient folder'.	
I do not have enough capacity in my clinical caseload to provide a 'patient folder'.	
I do not have enough resources to provide a 'patient folder'.	
There is not enough engagement from services for a 'patient folder' to be effective.	
There is not enough engagement from families for a 'patient folder' to be effective.	

6) **If you have anything further to add about barriers or have indicated that you do not think they are barriers (left the row blank), please explain your responses.**

Therapy specific topics

Note: We asked clinicians what information they currently provide on therapy specific topics (such as transfers, use of splints etc) during the transition from primary to secondary school for children with cerebral palsy.

We compared between the topics that physiotherapists tend to focus on, and those that occupational therapists tend to focus on.

The following three findings were noteworthy:

1) Physiotherapists and Occupational therapists provide information about a range of topics, but there are some topics that very few AHPs appear to provide information about.
These are listed in the table below.

7) **Please suggest what you think the barriers are to AHPs providing information about these topics**

	Barriers to provision
Mental health support	Free text box
Behavioural support	Free text box
Emotional support	Free text box
Female menstrual support	Free text box
Social Interaction	Free text box

2) The number of AHPs providing information about the topics was compared. For most topics, there were significant differences between the number of physiotherapists and occupational therapists providing information.
Please see the two tables below and provide your opinion about whether this is what you would expect based on your experience

Occupational therapists were found to provide significantly more information than physiotherapists about the following topics;

	8) Is this what you would expect?			
	Yes	**No**	**Not sure**	**Please expand**
Toileting				
Washing				
Dressing				
Occupational therapy exercises				

Aids to assist with eating/drinking				
Aids to assist with work i.e. pens etc				
Self-organisation skills				
Female menstruation support				

Physiotherapists were found to provide significantly more information than occupational therapists about the following topics;

	9) **Is this what you would expect?**			
	Yes	**No**	**Not sure**	**Please expand**
Physiotherapy exercises				
Walking including use of aids i.e. frame/sticks				
Stairs				
Use of splints or orthoses (i.e insoles)				

3) The number of AHPs providing information about all the topics was compared.
For 7 of the information topics, there was no significance towards either physiotherapists or occupational therapists providing this information.
We would like to gather your opinion on this.
Please see the table below.

10) **Please provide your opinion in regards to why there is no significant difference between physiotherapists or occupational therapists providing information about these topics in particular.**

	Please provided your opinion
Transfers	
Access to leisure activities (including sports clubs)	
Access to buildings/environment	
Social interaction	
Mental health support	
Behavioural support	
Emotional support	

Experiences

We asked clinicians (Physiotherapists/Occupational therapists) about thier experiences when providing information for caregivers of children with cerebral palsy at the transition from primary to secondary school.
They outlined the following positives of providing this information.

11) **Do you agree with the following positives of providing information at transition?**

	Strongly agree	**Agree**	**Disagree**	**Strongly Disagree**
I feel providing information at transition helps to create a smooth transition for the child				
I feel providing information at transition helps to improve the knowledge and understanding of people working with the child				

I feel that providing information at transition is positive as it gives people something to refer back to in future.				
I feel that providing information at transition helps to inform and support people working with the child				
I feel that providing information at transition can help to improve the independence/inclusion/participation of the child at secondary school				
I feel providing information at transition can improve the continuity of care				
I feel that providing information at transition can improve the outcomes/compliance of therapy.				
I feel that providing information at transition can help to alleviate anxiety around transition (both staff and the child)				
I feel that providing information at transition it useful for preparation prior to starting secondary school.				

Following this we asked clinicians if they have experienced barriers providing information to caregivers of children with cerebral palsy moving from primary to secondary school.

They outlined a total of 15 barriers.

These barriers have been grouped into subcategories for ease of ranking.

Barriers associated with provision of health services (physiotherapy/occupational therapy), those associated with education provision (including school staff) and barriers directly related to caregivers or children.

12) **Barriers associated with health service provision (physiotherapy/occupational therapy). For the following barriers please rank them from the most significant (Rank 1) to the least significant (Rank 7). If you do not consider it to be a barrier please leave the row blank.**

	Rank
I feel poor communication between services (such as between education and health) is a barrier to information provision at transition	
I feel poor information sharing between services (such as between education and health) is a barrier to information provision at transition.	
I feel that lack of accountability or responsibility of staff is a barrier to information provision at transition.	
I feel the lack of time is a barrier to information provision at transition.	
I feel the lack of resources and funding (such as timely provision of equipment) is a barrier to information provision at transition.	
I feel my clinical capacity (current size of caseload) is a barrier to information provision at transition.	

I feel that I am unable to provide and maintain up to date information and this is a barrier to information provision at transition.	

13) **Barriers associated with education provision (school/staff). For the following barriers please rank the barriers from most significant (Rank 1) to least significant (Rank 6). If you do not consider it to be barrier please leave the row blank.**

	Rank
I feel poor communication between services (such as between education and health) is a barrier to information provision at transition	
I feel poor information sharing between services (such as between education and health) is a barrier to information provision at transition	
I feel like the increased number of staff involved with the child at secondary school is a barrier to information provision at transition.	
I feel the availability of staff (both health and education) is a barrier to information provision at transition.	
I feel the late notice and lack of uncertainty of school/staff allocation for secondary school is a barrier to information provision at transition	
I feel the lack of awareness and understanding of staff working with children in the secondary school environment is a barrier to information provision at transition.	

14) **Barriers associated with caregivers/children. For the following barriers please rank them from most significant (Rank 1) to least significant (Rank 4). If you do not consider it to be a barrier then please leave the row blank.**

	Rank
I feel communication difficulties with caregivers (for example language barriers/additional needs) is a barrier to information provision at transition	
I feel the volume of information provided from lots of different sources around the time of transition is a barrier.	
I feel that the fear of transition by children and the need for acceptance is a barrier to information provision at transition.	
I feel the lack of knowledge around information needs of caregivers is a barrier to information provision at transition.	

15) **Considering the above subcategories of barriers. Which do you think are the most overall significant barriers?**

Barriers associated with health service provision
Barriers associated with education provision (school/staff)
Barriers associated with caregivers/children

Finally, we asked clinicians if they had any suggestions of how to overcome the barriers which they presented.
The suggestions were summarised as follows;

16) **Do you agree with the following suggested ways to overcome barriers to providing information at transition?**

	Strongly agree	Agree	Disagree	Strongly Disagree
I feel that the generation of specific training for educational staff at transition would overcome the barriers to information provision at transition.				
I feel that protected time for staff (both health and education) at transition would overcome the barriers to information provision at transition.				
I feel that having an identified lead person would overcome the barriers to information provision at transition.				
I feel that improved communication would overcome the barriers to information provision at transition.				
I feel that improved understanding of educational staff would overcome the barriers to information provision at transition.				
I feel that individualisation information for education staff would overcome the barriers to information provision at transition.				
I feel that increased pre-planning (prior to year 6 primary school) would overcome the barriers to information provision at transition.				
I feel that the use of pre-visits/meetings would overcome the barriers to information provision at transition.				
I feel that nationally produced standardised information/advice (i.e. apps/leaflets/website) would overcome the barriers to information provision at transition.				
I feel that there needs to be improvements in MDT approach and planning to overcome the barriers to information provision at transition.				
I feel a buddy system/support system using other families would help overcome the barriers to information provision at transition.				
I feel that reduced caseloads (caseload management) would overcome the barriers to information provision at transition.				
I feel that access to education staff in the summer holidays would overcome the barriers to information provision at transition.				

17) If you should wish please expand of your above choices

18) Do you have anything else that you wish to add?

Thank you page

Thank you for taking the time to complete this questionnaire.

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Caregiver questionnaire – Cg2

Introduction

Thank you for consenting to receive the second questionnaire in relation to the study you participated in earlier this year.

Study Title: Physiotherapy and Occupational therapy information needs of caregivers of children with cerebral palsy, living in the United Kingdom, during the transition from primary to secondary school.

The results of the first questionnaire have now been collated. We would be very grateful for your comments on the results from the first phase of the study.

If you have any questions regarding the study please do not hesitate to contact me.

Yours Sincerely,
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Demographic Information

1) **What would best describe your relationship to the child?**
   Mother
   Father
   Grandmother
   Grandfather
   Carer
   Other
2) **Is your child male or female?**
   Male
   Female
3) **Which are of the United Kingdom do you live?**
   England
   Scotland
   Wales
   Northern Ireland

Use of 'Patient Folders'

In our previous questionnaire we asked clincians (physiotherapists and occupational therapists) about the use of a 'patient folder' in clinical practice. 'Patients folders' are suggested within guidelines as a way to help provide information.
75% of clinicians (physiotherapists/occupational therapists) who responded had not or did not use this in their practice and identified several barriers for not using this.

4) Have you ever experienced the use of a 'patient folder'?

Yes/No

No – 5) Do you think this would be helpful to you as a caregiver?

6) How/What do you think this would be helpful to you as a caregiver?

Yes – 5) How/Why was this helpful to you as a caregiver?

Parents who responded to our questionnaire reported that they would like more information on all of the suggested 'therapy specific' topics, such as toiletting and exercises.

7) Why do you think parents said 'yes' to more information on all topics?

Free Text Box

Therapy specific topics

We asked clinicians what information they currently provide on therapy specific topics (such as transfers, use of splints etc) during the transition from primary to secondary school for children with cerebral palsy.
We compared between the topics that physiotherapists tend to focus on, and those that Occupational therapists tend to focus on.
The following findings were noteworthy:

1) Physiotherapists and Occupational therapists provide information about a range of topics, but there are some topics that very few allied health professionals (AHPs) appear to provide information about.
These are listed in the table below.

8) Please suggest what you think the barriers are to AHPs providing information about these topics

	Barriers to provision
Mental health support	Free text box
Behavioural support	Free text box
Emotional support	Free text box
Female menstrual support	Free text box
Social Interaction	Free text box

2) The number of allied health profesionals providing information about the topics was compared. For most topics, there were significant differences between the number of physiotherapists and occupational therapists providing information.

Please see the two tables below and provide your opinion about whether this is what you would expect based on your experience

9) Occupational therapists were found to provide significantly more information than physiotherapists about the following topics;

	Is this what you would expect?					
	Yes	**No**	**Not sure**	**Please expand**	**Who wold you like to provide this information?**	**When would you like to receive information about this topic?**
Toileting						
Washing						
Dressing						
Occupational therapy exercises						
Aids to assist with eating/drinking						
Aids to assist with work i.e. pens etc						
Self-organisation skills						

Female menstruation support						

10) Physiotherapists were found to provide significantly more information than occupational therapists about the following topics;

	Is this what you would expect?					
	Yes	**No**	**Not sure**	**Please expand**	**Who wold you like to provide this information?**	**When would you like to receive information about this topic?**
Physiotherapy exercises						
Walking including use of aids i.e. frame/sticks						
Stairs						
Use of splints or orthoses (i.e insoles)						

3) The number of AHPs providing information about all the topics was compared.
For 7 of the information topics, there was no significance towards either physiotherapists or occupational therapists providing this information.

We would like to gather your opinion on this.
Please see the table below.

11) Please provide your opinion in regards to why there is no significant difference between physiotherapists or occupational therapists providing information about these topics in particular.

	Who would you like to provide information on this topic?	**When would you like to receive information about this topic?**
Transfers		
Access to leisure activities (including sports clubs)		
Access to buildings/environment		
Social interaction		
Mental health support		
Behavioural support		
Emotional support		

Experiences

We asked clinicians (Physiotherapists/Occupational therapists) about their experiences when providing information for caregivers of children with cerebral palsy at the transition from primary to secondary school.
They outlined the following positives of providing this information.

12) Do you agree with the following positives of providing information at transition?

	Strongly agree	Agree	Disagree	Strongly Disagree
I feel providing information at transition helps to create a smooth transition for the child				
I feel providing information at transition helps to improve the knowledge and understanding of people working with the child				
I feel that providing information at transition is positive as it gives people something to refer back to in future.				
I feel that providing information at transition helps to inform and support people working with the child				
I feel that providing information at transition can help to improve the independence/inclusion/participation of the child at secondary school				
I feel providing information at transition can improve the continuity of care				
I feel that providing information at transition can improve the outcomes/compliance of therapy.				
I feel that providing information at transition can help to alleviate anxiety around transition (both staff and the child)				
I feel that providing information at transition it useful for preparation prior to starting secondary school.				

Following this we asked clinicians if they have experienced barriers providing information to caregivers of children with cerebral palsy moving from primary to secondary school.

They outlined a total of 15 barriers.

These barriers have been grouped into subcategories for ease of ranking.

Barriers associated with provision of health services (physiotherapy/occupational therapy), those associated with education provision (including school staff) and barriers directly related to caregivers or children.

13) Barriers associated with health service provision (physiotherapy/occupational therapy). For the following barriers please rank them from the most significant (Rank 1) to the least significant (Rank 7). If you do not consider it to be a barrier please leave the row blank.

	Rank
I feel poor communication between services (such as between education and health) is a barrier to information provision at transition	
I feel poor information sharing between services (such as between education and health) is a barrier to information provision at transition.	
I feel that lack of accountability or responsibility of staff is a barrier to information provision at transition.	
I feel the lack of time is a barrier to information provision at transition.	

I feel the lack of resources and funding (such as timely provision of equipment) is a barrier to information provision at transition.	
I feel my clinical capacity (current size of caseload) is a barrier to information provision at transition.	
I feel that I am unable to provide and maintain up to date information and this is a barrier to information provision at transition.	

14) Barriers associated with education provision (school/staff). For the following barriers please rank the barriers from most significant (Rank 1) to least significant (Rank 6). If you do not consider it to be barrier please leave the row blank.

	Rank
I feel poor communication between services (such as between education and health) is a barrier to information provision at transition	
I feel poor information sharing between services (such as between education and health) is a barrier to information provision at transition	
I feel like the increased number of staff involved with the child at secondary school is a barrier to information provision at transition.	
I feel the availability of staff (both health and education) is a barrier to information provision at transition.	
I feel the late notice and lack of uncertainty of school/staff allocation for secondary school is a barrier to information provision at transition	
I feel the lack of awareness and understanding of staff working with children in the secondary school environment is a barrier to information provision at transition.	

15) Barriers associated with caregivers/children. For the following barriers please rank them from most significant (Rank 1) to least significant (Rank 4). If you do not consider it to be a barrier then please leave the row blank.

	Rank
I feel communication difficulties with caregivers (for example language barriers/additional needs) is a barrier to information provision at transition	
I feel the volume of information provided from lots of different sources around the time of transition is a barrier.	
I feel that the fear of transition by children and the need for acceptance is a barrier to information provision at transition.	
I feel the lack of knowledge around information needs of caregivers is a barrier to information provision at transition.	

16) Considering the above subcategories of barriers. Which do you think are the most overall significant barriers?

Barriers associated with health service provision
Barriers associated with education provision (school/staff)
Barriers associated with caregivers/children

17) In your experience as a caregiver, do you think there are any further barriers to providing information at transition?

Free text Box

Finally, we asked clinicians if they had any suggestions of how to overcome the barriers which they presented.
The suggestions were summarised as follows;

18) Do you agree with the following suggested ways to overcome barriers to providing information at transition?

	Strongly agree	**Agree**	**Disagree**	**Strongly Disagree**
I feel that the generation of specific training for educational staff at transition would overcome the barriers to information provision at transition.				
I feel that protected time for staff (both health and education) at transition would overcome the barriers to information provision at transition.				
I feel that having an identified lead person would overcome the barriers to information provision at transition.				
I feel that improved communication would overcome the barriers to information provision at transition.				
I feel that improved understanding of educational staff would overcome the barriers to information provision at transition.				
I feel that individualisation information for education staff would overcome the barriers to information provision at transition.				
I feel that increased pre-planning (prior to year 6 primary school) would overcome the barriers to information provision at transition.				
I feel that the use of pre-visits/meetings would overcome the barriers to information provision at transition.				
I feel that nationally produced standardised information/advice (i.e. apps/leaflets/website) would overcome the barriers to information provision at transition.				
I feel that there needs to be improvements in MDT approach and planning to overcome the barriers to information provision at transition.				
I feel a buddy system/support system using other families would help overcome the barriers to information provision at transition.				
I feel that reduced caseloads (caseload management) would overcome the barriers to information provision at transition.				
I feel that access to education staff in the summer holidays would overcome the barriers to information provision at transition.				

19) In your experience as a caregiver, do you have any other suggestions of ways to overcome barriers of providing information at transition?

Free text Box

20) Do you have anything else that you wish to add?

Free text Box

Thank you page

Thank you for taking the time to complete this questionnaire.

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9.4 Appendix 4

9.4.1 4a) Participant information sheet – clinicians

Appendix- Participant Information Sheet- PT/OT

Participant Information Sheet – PT/OT group

Study Title: Physiotherapy and Occupational Therapy information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.

1. Invitation

Transition from primary to secondary school is a key stage in the development of independence, with children more often than not moving into a new and larger environment with reduced parental access and involvement. The transition of children from primary to secondary school education, within the United Kingdom (UK), is known to be a highly stressful time for families. Caregivers of children with Cerebral Palsy (CP) are no different. Children with CP are known to have a higher level of need in order to successfully manage their condition. Currently, there is no standardised therapy specific information in the UK to support Caregivers to empower their children and assist children with the self-management of their condition. Guidelines, such as NICE (2017), provide a 'gold standard' in regards to suggested information provision however it is currently unknown how this is translated into clinical practice.

Physiotherapists (PTs) and occupational therapists (OTs) play an important role in providing information to help support children with disabilities to achieve their full functional potential and work towards independent management of their condition. In order to develop standardised information, that can support families during the transition from primary to secondary school education, it is important to understand the current practices throughout the UK and the current information needs of caregivers of children with CP. Therefore, this study aims to explore these current needs and practices on a national scale.

This study is part of a postgraduate research project as part of a Masters in Clinical Research. This information sheet will tell you what the study is about and what it will involve if you decide to take part. If you require any additional information, please contact Amy Howells, postgraduate student, whose details are at the end of the information sheet.

2. What is the purpose of the study?

PTs and OTs play an important role in helping children with CP to fulfil their functional potential and are key in sharing information with caregivers. Currently there is no standard in the UK to provide information to caregivers of children with CP during the transition from primary school to secondary school education.

This study aims to find out the following;

1) What information is currently provided by PTs and OTs to caregivers of children with CP during the transition from primary to secondary school?
2) How is information currently given by PTs and OTs to caregivers of children with CP during the transition from primary to secondary school?
3) What are caregivers experiences of good practice when receiving information from PTs and OTs regarding transition from UK primary to secondary school education of children with CP?
4) What is missing from the current information provided by PTs and OTs to caregivers of children with CP as they transition from UK primary to secondary school education?
5) Do caregivers have any ideas on how PTs and OTs should share information during their child's transition from primary to secondary school?

3. Why have I been invited?

You have been invited to take part in this study as you are either a physiotherapist or occupational therapist who works in the UK with children with a diagnosis of CP. You should have experience of supporting families through the transition from primary school to secondary school.

4. Do I have to take part?

The study is voluntary and it is up to you if you wish to take part. If you are considering taking part then please read all the information provided, which will explain the study in more depth. If you do not wish to take part, you do not need to do anything further.

5. What will happen to me if I take part?

The following questionnaire will ask about your experiences of providing information to families of children with cerebral palsy as they transition from primary to secondary school. No questions will be asked that might allow the research team to identify you. The questionnaire is anonymous and should take between 10-20 minutes to complete. The survey link will

be open for approximately 6 weeks. At the end of the questionnaire there will be an opportunity for you to supply an email address, in case you wish to withdraw your responses; if you wish to withdraw your responses, you will be able to do so within 2 weeks of the date that you respond. If you do not provide an email address you will **not** be able to withdraw your responses. You will be asked at the end of the study if you would be happy to be contacted by the research team at a later date to take part in phase 2 of the study. You are not obliged to take part in phase 2 of the study.

6. What are the possible benefits of taking part?

It is unlikely that you will gain any personal benefits from the study, however the information gathered may help to highlight the areas of good practice and gaps in service provision. We hope that the information gained from the study may inform the basis of improving the processes of sharing information with caregivers of children with CP across the UK during the transition from primary to secondary school.

7. What are the possible disadvantages and risks of taking part?

There are not considered to be any significant risks of harm to taking part in the study however completing the form may highlight sensitive issues within your clinical role.

Should you require any support following completing the questionnaire you should approach your local trust support services or the support services available from your professional body.

8. Will my taking part in the study be kept confidential?

There will be no personal details collected from you within the study. Demographic information collected within the questionnaire will not be identifiable – this means that any questions asked about you would not enable members of the research team to know who you are. All information collected throughout the study will be anonymous unless you choose to supply an email address as outlined above. If you choose to provide your contact information, this will be stored confidentially, only known to the researcher named above. The other members of the research team will only access anonymous data. Data collected throughout the study will be stored securely, on a password-protected computer.

9. What will happen to the results of the research study?

It is hoped that the findings of the study will be used to make recommendations for practice and may potentially inform future research into how caregivers of children with a diagnosis of CP information needs are met by PTs and OTs, as they transition from primary to secondary school. There is a potential that the findings will be submitted for publication in healthcare journals and it is hoped that they will be presented as conference papers/posters as a way of sharing good practice with other healthcare practitioners.

10. Can I withdraw from the study?

As the questionnaire is anonymous, you will not be able to withdraw your answers, unless you submit an email address when asked at the end of the questionnaire.

As you have received this link via an organisation, the researcher does not hold any of your personal details. It will therefore not be possible to trace your answers unless you submit an email address. It is possible to request that your data be withdrawn within the 2 week period after submitting your responses; after this time, anonymised responses will be collated and it will not be possible to identify your data.

If you wish to remain anonymous throughout the questionnaire then please do not submit an email address.

11. Who has reviewed the study?

The study has been granted ethical approval by Coventry University [P61846]. The study is being undertaken under the supervision of Dr Tanya Rihtman, Dr Joanne Opie and Dr Simon Igo, and complies with the principles of research governance in healthcare research.

12. What if there is a problem?

In the unlikely event that anything goes wrong, or if you are discontented with any aspect of the research process, you can contact Prof Olivier Sparagono (Associate Pro Vice Chancellor (Research) with any concerns: Iras-sponsor@coventry.ac.uk Address: Coventry University, Priory St, Coventry CV1 5FB Tel: 024 7688 7688.

You are also able to contact the research supervisor named below at any point.

13. Contact for further information?

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9.4.2 4b) Participant information sheet – caregivers

Appendix – Participant Information Sheet- Caregivers

Participant Information Sheet – Caregivers Group

Study Title: Physiotherapy and Occupational Therapy information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.

1. Invitation

Transition from primary to secondary school is a key stage in the development of independence, with children more often than not moving into a new and larger environment with reduced parental access and involvement. The transition of children from primary to secondary school education, within the United Kingdom (UK), is known to be a highly stressful time for families. Caregivers of children with Cerebral Palsy are no different. Children with Cerebral Palsy are known to have a higher level of need in order to successfully manage their condition. Currently, there is no standardised therapy specific information in the UK to support Caregivers to empower their children and assist children with the self-management of their condition. Guidelines, such as NICE (2017), provide a 'gold standard' in regards to suggested information provision however it is currently unknown how this is translated into clinical practice.

Physiotherapists (PTs) and occupational therapists (OTs) play an important role in providing information to help support children with disabilities to achieve their full functional potential and work towards independent management of their condition. In order to develop standardised information, that can support families during the transition from primary to secondary school education, it is important to understand the current practices throughout the UK and the current information needs of caregivers of children with Cerebral Palsy. Therefore, this study aims to explore these current needs and practices on a national scale.

This study is part of a postgraduate Masters degree in Clinical Research. This information sheet will tell you what the study is about and what it will involve if you decide to take part. If you require any additional information, please contact Amy Howells, postgraduate student, whose details are at the end of the information sheet.

2. What is the purpose of the study?

PTs and OTs play an important role in helping your child to fulfil their functional potential and providing families with information to support with managing their child's condition. Currently there is no standard in the UK to provide information to caregivers of children with Cerebral Palsy during the period when they move from primary school to secondary school education.

This study aims to find out the following;

1) What information is currently provided by PTs and OTs to caregivers of children with cerebral palsy during the transition from primary to secondary school?
2) How is information currently given by PTs and OTs to caregivers of children with cerebral palsy during the transition from primary to secondary school?
3) What are caregivers experiences of good practice when receiving information from PTs and OTs regarding transition from UK primary to secondary school education of children with cerebral palsy?
4) What is missing from the current information provided by PTs and OTs to caregivers of children with cerebral palsy as they transition from UK primary to secondary school education?
5) Do caregivers have any ideas on how PTs and OTs should share information during their child's transition from primary to secondary school?

3. Why have I been invited?

You have been invited to take part in this study as you are a caregiver for a child with a diagnosis of Cerebral Palsy, who is due to transition from primary to secondary school in September 2018 or has transitioned in the previous two years (2016 or 2017). You live in the United Kingdom and your child is currently receives physiotherapy and/or occupational therapy or received physiotherapy and/or occupational therapy during the period they moved from primary to secondary school.

4. Do I have to take part?

The study is voluntary and it is up to you if you wish to take part. If you are considering taking part then please read all the information provided, which will explain the study in more depth. If you do not wish to take part, you do not need to do anything further. Not taking part will not affect the care your child receives.

5. What will happen to me if I take part?

During the following questionnaire you will be asked to answer some questions about you and your child. You will be asked about your experiences of receiving information during the period when you supported your child in their transition from

primary to secondary school. No questions will be asked that might allow the research team to identify you. The questionnaire is anonymous and should take no longer than [insert time, which will be finalised at pilot, here]. The survey link will be open for approximately 6 weeks. At the end of the questionnaire there will be an opportunity for you to supply an email address, in case you wish to withdraw your responses; if you wish to withdraw your responses, you will be able to do so within 2 weeks of the date that you respond. If you do not provide an email address you will **not** be able to withdraw your responses. You will be asked at the end of the study if you would be happy to be contacted by the research team at a later date to take part in phase 2 of the study. You are not obliged to take part in phase 2 of the study.

6. What are the possible benefits of taking part?

It is unlikely that you will gain any personal benefits from the study, however the information gathered from this study may help to improve the level of information available for caregivers of children with cerebral palsy across the UK during the transition from primary to secondary school.

7. What are the possible disadvantages and risks of taking part?

There are not considered to be any significant risks of harm to taking part in the study however completing the questionnaire may require you to consider sensitive experiences when thinking about your child's diagnosis.

Should you require any support following completion of the questionnaire, you could approach your GP or healthcare professionals such as your Practice Nurse, Physiotherapist or Occupational Therapist.

8. Will my taking part in the study be kept confidential?

There will be no personal details collected from you within the study. Demographic information collected within the questionnaire will not be identifiable - this means that any questions asked about you or your child would not enable members of the research team to know who you are. All information collected throughout the study will be anonymous unless you choose to supply an email address as outlined above. If you choose to provide your contact information, this will be stored confidentially, only known to the researcher named above. The other members of the research team will only access anonymous data. Data collected throughout the study will be stored securely, on a password-protected computer.

9. What will happen to the results of the research study?

It is hoped that the findings of the study will be used to make recommendations for practice, and may potentially inform future research into how caregivers of children with a diagnosis of Cerebral Palsy information needs are met by PTs and OTs, as they transition from primary to secondary school. There is also the potential that the findings will be submitted for publication in healthcare journals and it is hoped that they will be presented as conference papers/posters as a way of sharing good practice with other healthcare practitioners.

10. Can I withdraw from the study?

As the questionnaire is anonymous, you will not be able to withdraw your answers, unless you submit an email address when asked at the end of the questionnaire.

As you have received this link via an organisation, the researcher does not hold any of your personal details. It will therefore not be possible to trace your answers unless you submit an email address. It is possible to request that your data be withdrawn within the 2 week period after submitting your responses; after this time, anonymised responses will be collated and it will not be possible to identify your data.

If you wish to remain anonymous throughout the questionnaire then please do not submit an email address.

11. Who has reviewed the study?

The study has been granted ethical approval by Coventry University [state university ethics application number here]. The study is being undertaken under the supervision of Dr Tanya Rihtman, Dr Joanne Opie and Dr Simon Igo, and complies with the principles of research governance in healthcare research.

12. What if there is a problem?

In the unlikely event that anything goes wrong, or if you are discontented with any aspect of the research process, you can contact Prof Olivier Sparagono (Associate Pro Vice Chancellor (Research) with any concerns: Iras-sponsor@coventry.ac.uk
Address: Coventry University, Priory St, Coventry CV1 5FB Tel: 024 7688 7688

You are also able to contact the research supervisor named below at any point.

13. Contact for further information?

Content removed on data protection grounds

9.4.3 4c) Informed consent – both participant groups

Informed Consent Statement

University Ethics No:

Consent Form

Study Title: Physiotherapy and Occupational Therapy information needs of caregivers of children, living within the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.

Please tick each box;

1. I confirm that I have read the information sheet for the study described above. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation in this study is voluntary.

3. I understand that all data collected within the study will be anonymous and therefore once I have submitted my questionnaire it will not be possible for me to withdraw my answers unless I submit an email address when offered.

4. I understand that to be able to withdraw my responses I will need to submit an email address. I will have 2 weeks after responding to the survey to withdraw my responses if I change my mind about participation. I understand that by giving my email address my responses will no longer be anonymous.

5. I understand by submitting my email address at the end of the questionnaire, I am consenting to the researcher contacting me to invite me to complete a second questionnaire at a later date. I understand that I am not obliged to respond to the second questionnaire if I do not wish to.

6. I agree to the use of anonymous data in all publications generated from this study and understand that data collected may be used to support other research in the future.

7. I agree to take part in the above study.

9.5 Appendix 5

9.5.1 5a) Ethics application

Physiotherapy and Occupational Therapy Information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.

P61846

Medium to High Risk Research Ethics Approval

Project Title

Physiotherapy and Occupational Therapy Information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.

Record of Approval

Principal Investigator

I **request an ethics peer review** and confirm that I have answered all relevant questions in this checklist honestly	X
I confirm that I will carry out the project in the ways described in this checklist. I will immediately suspend research and request new ethical approval if the project subsequently changes the information I have given in this checklist.	X
I confirm that I, and all members of my research team (if any), have read and agreed to abide by the Code of Research Ethics issued by the relevant national learned society.	X
I confirm that I, and all members of my research team (if any), have read and agreed to abide by the University's Research Ethics, Governance and Integrity Framework	X

Name: Amy Howells .....

Date: 06/10/2017 .....

Student's Supervisor (if applicable)

I have read this checklist and confirm that it covers all the ethical issues raised by this project fully and frankly. I also confirm that these issues have been discussed with the student and will continue to be reviewed in the course of supervision.

Name: Tanya Rihtman .....

Date: 04/05/2018 .....

Reviewer (if applicable)

Date of approval by anonymous reviewer: 09/05/2018

Medium to High Risk Research Ethics Approval Checklist

Project Information

Project Ref	P61846
Full name	Amy Howells
Faculty	Faculty of Health and Life Sciences
Department	Other
Supervisor	Tanya Rihtman
Module Code	MRes-CIRAL
EFAAF Number	
Project title	Physiotherapy and Occupational Therapy Information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.
Date(s)	01/04/2018 - 26/05/2019
Created	06/10/2017 14:19

Project Summary

Despite NICE guideline (2017) suggestions, current therapy-specific information needs of UK caregivers of children with CP, during transition from primary to secondary school are unknown. Transition is known to be a difficult phase for all children. Children with CP are no different and often require additional support. Physiotherapists (PTs) and occupational Therapists (OTs) play a key role in providing information however there is no standard therapy-specific information in the UK to support management of this life stage.

This study aims to explore the current PT and OT information needs of caregivers of children, living in the UK with a diagnosis of CP, during the transition from primary to secondary school.

A mixed-method survey design, in two phases, using Bristol Online Survey will be used. Participants will be recruited via convenience sampling for piloting. Using gatekeepers, non-probability sampling will support recruitment (Phases 1&2) to three groups: Caregivers, PTs and OTs. Results from Phase 1 will be presented to participants for review during Phase 2. Data will be analysed using relevant quantitative methods with non-numerical data to support these findings.

Names of Co-Investigators and their organisational affiliation (place of study/employer)	
Is the project self-funded?	YES
Who is funding the project?	NIHR/HEE
Has the funding been confirmed?	YES

Are you required to use a Professional Code of Ethical Practice appropriate to your discipline?	YES
Have you read the Code?	YES

Project Details

What is the purpose of the project?	Research Question: What are the current PT and OT information needs of UK caregivers of children with a diagnosis of CP, during the transition from primary school to secondary school? Study Aim: To explore the current PT and OT information needs of UK caregivers of children with a diagnosis of CP, during the transition from primary school to secondary school. Study Objectives: Explore what information is currently provided by PTs and OTs to caregivers of children with CP as they transition from primary to secondary school. Explore how information is currently provided by PTs and OTs to caregivers of children with CP as they transition from primary to secondary school. Explore caregivers experiences of good practice when receiving information from PTs and OTs regarding transition from primary to secondary school of children with CP. Explore gaps in the nature and means of information provision provided by PTs and OTs to caregivers of children with CP as they transition from primary to secondary school. Identify caregiver-informed strategies for

	future information provision from PTs and OTs to caregivers of children with CP as they transition from primary to secondary school.
What are the planned or desired outcomes?	The proposed study has the potential to highlight areas of good practice yet also gaps in service provision, throughout the UK, in regards to therapy services meeting caregivers' information needs for their child with CP as they transition from primary to secondary school.
	important experiences and needs of caregivers, which could be shared throughout the population of practising paediatric PTs and OTs. The study has the potential to share areas of good practice, potentially showcasing where guidelines have been implemented effectively or ineffectively, decreasing duplication of projects throughout the country. The study findings could potentially inform future research into a suitable information provision to meet highlighted needs.

Explain your research design	This study will follow an empirical descriptive survey method as per Simm and Wright (2000). Pilot will focus on design, content and usability of the questionnaire. PHASE 1: Online questionnaire collecting responses from three participant groups; 1) Caregivers 2) Physiotherapists (PTs) 3) Occupational Therapists (OTs) Questionnaire will collect quantitative data alongside non-numerical data in order to support and contextualise findings. PHASE 2: Online questionnaire will collect qualitative responses from same three participant groups (Caregivers, PTs, OTs) for verification of phase 1 results. Sample size of 20 per participant group is sufficient for the aim of the exploratory study to provide a descriptive account of the current information needs of parents/carers of children with CP throughout the UK. A research diary will be kept with key decision making shown, adherence to boundaries of good research and no influence of personal values.

	All responses will be collected directly onto the Bristol Online Survey (BOS) programme therefore reducing human error in transcription of data.
Outline the principal methods you will use	Non-probability sampling will be used. Participants will be recruited via gatekeepers to three groups (caregivers/PTs/OTs). PHASE 1: Aim to recruit approx. 20 participants from each participant group. PHASE 2: Aim to recruit approx. 6 participants from each participant group; these may or may not be respondents who participated in phase 1. The following inclusion and exclusion criteria will be used in order to recruit. Group 1: Caregivers Inclusion; Caregiver of a child with a diagnosis of CP who is due to transition from Primary to Secondary School in September 2018 or has transitioned within the last two years (2016-17 or 2017-18). Caregiver of Children with CP who were living within the UK during the period of transition from primary to secondary school. Caregiver of children who are currently receiving PT and/or OT or who received either PT and/or OT treatment during their transition to secondary school. Exclusion; Caregiver of children with a primary diagnosis other than CP, including chronic illnesses (for example, cancer, rheumatoid arthritis, asthma), syndromes (for example downs syndrome), Autistic

	spectrum disorder, attention deficit/hyperactivity disorder, developmental co-ordination disorder and acquired traumatic brain injuries. Caregiver of children who have not received either PT or OT treatment. Caregiver of children who live outside the UK or lived outside of the UK when their child transitioned from primary to secondary school. Group 2 & 3: PTs/OTs Inclusion; Heath Care Professions Council (HCPC) registered PT/OT Practising within the UK. PTs/OTs who have at least 18 months experience of working with caregivers who have a child with a diagnosis of CP. with a diagnosis of CP. PTs/OTs working with children with a diagnosis of CP as they transition from Primary to Secondary School. Exclusion; PTs/OTs who are not HCPC registered. PTs/OTs who do not work with children with CP as part of their caseload. Pilot Phase: For pilot a convenience sample of 1 PT and 1 OT for comment on content and usability of caregiver questionnaire and completion of the PT/OT questionnaire will be used. This convenience sample will be recruited via gatekeepers via letter (Appendix 1). Pilot participant letter will be embedded into the questionnaire (Appendix 2) with additional questions at the end of the questionnaire.

	After the piloting process, participants will be recruited via letter (Appendix 3) to theto the following: PTs/OTs: Professional networks/organisations as Gatekeepers. PTs and OTs will not be recruited via their place of work and none of the data gathering will occur within their places of work (e.g. NHS); as such, IRAS approval will not be required. Caregivers: Voluntary/Non-Statutory Organisations. Through gatekeepers, participants will be able to access an anonymous BOS link. PHASE 1: Participants will be provided with an embedded Participant information sheet (one for caregivers (Appendix 4) and one for PTs/OTs (Appendix 5)) and consent form (Appendix 6). Two different surveys will be developed, caregivers (Appendix 7) and PTs/OTs (Appendix 8). Phase 1 link will remain open for approx6 weeks. Questionnaire responses will be anonymous. Participants will be given the opportunity to provide an email address at the end of the questionnaire should they wish to be able to withdraw responses. This information will be kept separate from the main data during analysis. Participants will be asked to submit an email address if they consent to the

	research team contacting them at a later date to take part in Phase 2 of the study. It will be clear that participants have no obligation to complete this. PHASE 2: Phase 1 analysis will inform the generation of a phase 2 questionnaire as a form of member checking and verification of results. BOS will be used and questionnaire (caregiver or PT/OT version) shared via same gatekeepers as in phase 1. Phase 2 questionnaire will be open for approx. 6 weeks. See appendix 9 for flow chart of above.

Are you proposing to use an external research instrument, validated scale or follow a published research method?	YES
If yes, please give details of what you are using	Online questionnaire will be used through Bristol Online Survey. Participants will complete one of two questionnaires dependant on their participant group. Questionnaire items developed to address study objectives will be included, focusing around the recommendations for information and support as presented within the most current NICE guidelines (2017) for the management of children with cerebral palsy. Two different survey questionnaires will be used; (Caregivers Draft questionnaire- Appendix 7 or PT/OT Draft questionnaire - Appendix 8). 1) Caregivers a. Demographic Information b. Descriptive information on child's CP diagnosis c. Other items developed for the purpose of this study 2) PTs/OTs a. Demographic Information b. Other items developed for the purpose of this study
Will your research involve consulting individuals who support, or literature, websites or similar material which advocates, any of the following: terrorism, armed struggles, or political, religious or other forms of activism considered illegal under UK law?	NO

Are you dealing with Secondary Data? (e.g. sourcing info from websites, historical documents)	NO

Are you dealing with Primary Data involving people? (e.g. interviews, questionnaires, observations)	YES
Are you dealing with personal or sensitive data?	YES
Will the Personal or Sensitive data be shared with a third party?	NO
Will the Personal or Sensitive data be shared outside of the European Economic Area ("EEA")?	NO
Is the project solely desk based? (e.g. involving no laboratory, workshop or off-campus work or other activities which pose significant risks to researchers or participants)	NO
Are there any other ethical issues or risks of harm raised by the study that have not been covered by previous questions?	YES

If yes, please give further details	Consent: Embedded participant information sheet and consent form. Unable to withdraw unless email supplied: Clear worded statement to explain anonymity will be compromised if email supplied. Risk of inclusion of unrelated population: Strict inclusion and exclusion criteria used for each participant group. Sensitive context of data: details of who to contact will be provided on the participant information sheet. Coertion of participants: Participants will be contacted via Gatekeepers. Participants will not be contacted directly unless consented (consent provided in Phase 1 to be contacted for Phase 2).Maintain confidentiality - researcher will act in boundaries of good research practice. No identifiable data collected. Data Management and Storage: Data handled in line with Data Protection act (1998) and Data management plan (see attached document). Potential conflict of Interest – the researcher is an NHS Employee: No recruitment will take place via any NHS organisation or through clinical role. Participants will only be contacted via Gatekeepers. A research diary will be kept to ensure that the researcher acts within bounds of good practice.

DBS (Disclosure & Barring Service) formerly CRB (Criminal Records Bureau)

Question		Yes	No
1	Does the study require DBS (Disclosure & Barring Service) checks?		X
	If YES, please give details of the serial number, date obtained and expiry date		
2	If NO, does the study involve direct contact by any member of the research team:		
	a) with children or young people under 18 years of age?		X
	b) with adults who have learning difficulties, brain injury, dementia, degenerative neurological disorders?		X
	c) with adults who are frail or physically disabled?		X
	d) with adults who are living in residential care, social care, nursing homes, re-ablement centres, hospitals or hospices?		X
	e) with adults who are in prison, remanded on bail or in custody?		X
	If you have answered YES to any of the questions above please explain the nature of that contact and what you will be doing		

External Ethical Review

Question		Yes	No
1	Will this study be submitted for ethical review to an external organisation? (e.g. Another University, Social Care, National Health Service, Ministry of Defence, Police Service and Probation Office)		X
	If YES, name of external organisation		
2	Will this study be reviewed using the IRAS system?		X
3	Has this study previously been reviewed by an external organisation?		X

Confidentiality, security and retention of research data

	Question	Yes	No
1	Are there any reasons why you cannot guarantee the full security and confidentiality of any personal or confidential data collected for the study?		X
	If YES, please give an explanation		
2	Is there a significant possibility that any of your participants, and associated persons, could be directly or indirectly identified in the outputs or findings from this study?		X
	If YES, please explain further why this is the case		
3	Is there a significant possibility that a specific organisation or agency or participants could have confidential information identified, as a result of the way you write up the results of the study?		X
	If YES, please explain further why this is the case		
4	Will any members of the research team retain any personal of confidential data at the end of the project, other than in fully anonymised form?		X
	If YES, please explain further why this is the case		
5	Will you or any member of the team intend to make use of any confidential information, knowledge, trade secrets obtained for any other purpose than the research project?		X
	If YES, please explain further why this is the case		
6	Will you be responsible for destroying the data after study completion?	X	

	If NO, please explain how data will be destroyed, when it will be destroyed and by whom	

Participant Information and Informed Consent

	Question		Yes	No
1	Will all the participants be fully informed BEFORE the project begins why the study is being conducted and what their participation will involve?		X	
	If NO, please explain why			
2	Will every participant be asked to give written consent to participating in the study, before it begins?		X	
	If NO, please explain how you will get consent from your participants. If not written consent, explain how you will record consent			
3	Will all participants be fully informed about what data will be collected, and what will be done with this data during and after the study?		X	
	If NO, please specify			
4	Will there be audio, video or photographic recording of participants?			X
	Will explicit consent be sought for recording of participants?			
	If NO to explicit consent, please explain how you will gain consent for recording participants			
5	Will every participant understand that they have the right not to take part at any time, and/or withdraw themselves and their data from the study if they wish?		X	
	If NO, please explain why			

6	Will every participant understand that there will be no reasons required or repercussions if they withdraw or remove their data from the study?	X	
	If NO, please explain why		
7	Does the study involve deceiving, or covert observation of, participants?		X
	Will you debrief them at the earliest possible opportunity?		
	If NO to debrief them, please explain why this is necessary		

Risk of harm, potential harm and disclosure of harm

Question		**Yes**	**No**
1	Is there any significant risk that the study may lead to physical harm to participants or researchers?		X
	If YES, please explain how you will take steps to reduce or address those risks		
2	Is there any significant risk that the study may lead to psychological or emotional distress to participants?		X
	If YES, please explain how you will take steps to reduce or address those risks		
3	Is there any risk that the study may lead to psychological or emotional distress to researchers?		X
	If YES, please explain how you will take steps to reduce or address those risks		
4	Is there any risk that your study may lead or result in harm to the reputation of participants, researchers, or their employees, or any associated persons or organisations?		X

	If YES, please explain how you will take steps to reduce or address those risks		
5	Is there a risk that the study will lead to participants to disclose evidence of previous criminal offences, or their intention to commit criminal offences?		X
	If YES, please explain how you will take steps to reduce or address those risks		
6	Is there a risk that the study will lead participants to disclose evidence that children or vulnerable adults are being harmed, or at risk or harm?		X
	If YES, please explain how you will take steps to reduce or address those risks		
7	Is there a risk that the study will lead participants to disclose evidence of serious risk of other types of harm?		X
	If YES, please explain how you will take steps to reduce or address those risks		
8	Are you aware of the CU Disclosure protocol?	X	

Payments to participants

Question		**Yes**	**No**
1	Do you intend to offer participants cash payments or any kind of inducements, or reward for taking part in your study?		X
	If YES, please explain what kind of payment you will be offering (e.g. prize draw or store vouchers)		

Capacity to give valid consent

	Question	Yes	No
1	Do you propose to recruit any participants who are:		
	a) children or young people under 18 years of age?		X
	b) adults who have learning difficulties, mental health condition, brain injury, advanced dementia, degenerative neurological disorders?		X
	c) adults who are physically disabled?		X
	d) adults who are living in residential care, social care, nursing homes, re-ablement centres, hospitals or hospices?		X
	e) adults who are in prison, remanded on bail or in custody?		X
	If you answer YES to any of the questions please explain how you will overcome any challenges to gaining valid consent		
2	Do you propose to recruit any participants with possible communication difficulties, including difficulties arising from limited use of knowledge of the English language?		X
	If YES, please explain how you will overcome any challenges to gaining valid consent		
3	Do you propose to recruit any participants who may not be able to understand fully the nature of the study, research and the implications for them of participating in it or cannot provide consent themselves?		X
	If YES, please explain how you will overcome any challenges to gaining valid consent		

Recruiting Participants

Question		Yes	No
1	Do you propose to recruit any participants who are:		
a)	students or employees of Coventry University or partnering organisation(s)?		X
	If YES, please explain if there is any conflict of interest and how this will be addressed		
b)	employees/staff recruited through other businesses, voluntary or public sector organisations?	X	
	If YES, please explain how permission will be gained	Questionnaire will be shared via Gatekeeper organisations. One potential gatekeeper organisation is Association of Paediatric Chartered Physiotherapists. There are a number of regional groups/organisations of this nature to ensure the feasibility of accessing potential participants via this route. PTs and OTs will not be recruited via their place of work and none of the data gathering will occur within their places of work (e.g. NHS); as such, IRAS approval will not be required.	
c)	pupils or students recruited through educational institutions (e.g. primary schools, secondary schools, colleges)?		X
	If YES, please explain how permission will be gained		

d)	clients/volunteers/service users recruited through voluntary public services?		X
	If YES, please explain how permission will be gained		
e)	participants living in residential care, social care, nursing homes, re-ablement centres hospitals or hospices?		X
	If YES, please explain how permission will be gained		
f)	recruited by virtue of their employment in the police or armed forces?		X
	If YES, please explain how permission will be gained		
g)	adults who are in prison, remanded on bail or in custody?		X
	If YES, please explain how permission will be gained		
h)	who may not be able to refuse to participate in the research?		X
	If YES, please explain how permission will be gained		

Online and Internet Research

Question			Yes	No
1	Will any part of your study involve collecting data by means of electronic media (e.g. the Internet, e-mail, Facebook, Twitter, online forums, etc)?			X
	If YES, please explain how you will obtain permission to collect data by this means			
2	Is there a possibility that the study will encourage children under 18 to access inappropriate websites, or correspond with people who pose risk of harm?			X
	If YES, please explain further			
3	Will the study incur any other risks that arise specifically from the use of electronic media?			X
	If YES, please explain further			
4	Will you be using survey collection software (e.g. BoS, Filemaker)?		X	
	If YES, please explain which software		Bristol Online Survey.	
5	Have you taken necessary precautions for secure data management, in accordance with data protection and CU Policy?		X	
	If NO	please explain why not		
	If YES	Specify location where data will be stored	Data will gathered on the User account of Bristol Online Survey. Data exported from BOS will be stored on a password-protected harddrive. As per the Coventry University policy for research data management, the research data and records will be retained for as long as they are of continuing value to the researcher. Therefore data will be kept for	

			a minimum retention data of three years following publication or public release. Please see Data management plan (Appendix 10)		
		Planned disposal date	31/03/2025		
		If the research is funded by an external organisation, are there any requirements for storage and disposal?			X
		If YES, please specify details			

Languages

Question			Yes	No
1	Are all or some of the consent forms, information leaflets and research instruments associated with this project likely to be used in languages other than English?			X
	If YES, please specify the language[s] to be used			
2	Have some or all of the translations been undertaken by you or a member of the research team?			
	Are these translations in lay language and likely to be clearly understood by the research participants?			
	Please describe the procedures used when undertaking research instrument translation (e.g. forward and back translation), clarifying strategies for ensuring the validity and reliability or trustworthiness of the translation			
3	Have some or all of the translations been undertaken by a third party?			
	If YES, please specify the name[s] of the persons or agencies performing the translations			
	Please describe the procedures used when undertaking research instrument translation (e.g. forward and back translation), clarifying strategies for ensuring the validity and reliability of the translation			

Laboratory/Workshops

Question		Yes	No
1	Does any part of the project involve work in a laboratory or workshop which could pose risks to you, researchers or others?		X
	If YES: If you have risk assessments for laboratory or workshop activities you can refer to them here & upload them at the end, or explain in the text box how you will manage those risks		

Research with non-human vertebrates

Question		Yes	No
1	Will any part of the project involve animal habitats or tissues or non-human vertebrates?		X
	If YES, please give details		
	endangered?		

Blood Sampling / Human Tissue Analysis

Question		Yes	No
1	Does your study involve collecting or use of human tissues or fluids? (e.g. collecting urine, saliva, blood or use of cell lines, 'dead' blood)		X
	If YES, please give details		

Travel

Question		Yes	No
1	Does any part of the project require data collection off campus? (e.g. work in the field or community)		X

9.5.2 5b) HRA decision tool

HRA decision toolkit determined study as research which did not require REC/IRAS approval. Email confirmation was received by the West Midlands CRN.

Content removed on data protection grounds

9.6 Appendix 6

9.6.1 6a) Pilot participant letter

Pilot of Questionnaire

Study Title: Physiotherapy and Occupational Therapy information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.

Dear Colleague,

My name is Amy Howells and I am a postgraduate research student at Coventry University. I am undertaking a Masters in Clinical Research supported by Health Education England and National Institute of Health Research.

Current literature has shown that physiotherapists and occupational therapists play an important role in providing caregivers with information in order to support their child's condition management. It is also known that the transition to secondary school can be a stressful time for all children; this can be even more true for those managing a long-term condition such as cerebral palsy. There is a need to understand the current practises of physiotherapists and occupational therapists within the United Kingdom. We would also like to know how therapists use available clinical guidelines in their current practice. Alongside this, it is also necessary to understand the current experiences of caregivers and their current information needs.

The aim of this study is to explore the current physiotherapy and occupational therapy information needs of caregivers of children, living with the United Kingdom with a diagnosis of cerebral palsy, during the transition from primary school to secondary school education.

In order to achieve this aim I have developed an online questionnaire, one for therapists and one for caregivers using Bristol online survey. Prior to sending out the questionnaire, it is necessary to pilot the items to check if the questions are easy to understand, the structure is easy to follow and how long the questionnaire takes to complete.

You have been invited to take part in this study as you meet the inclusion criteria for physiotherapists or occupational therapist, having experience of working with children with cerebral palsy in the UK, particularly during the transition from primary to secondary school education. Therefore, you are best placed to provide feedback on the proposed questionnaire. Following the questionnaire, you will be asked several questions which will be used to amend the questionnaire where necessary.

I would be grateful if you would complete the questionnaire for therapists in full, with accurate responses. Should the therapist questionnaire require no alterations following your feedback please be informed that your responses will be used within the study. In relation to the caregiver questionnaire, I would appreciate your feedback in response to content, design and usability. You are not expected to submit any responses for this questionnaire.

Feedback questions will follow the online questionnaire.

If you are willing to participate, please continue with the following questionnaire;

If you have any questions regarding the above, please do not hesitate to contact me,

Yours Sincerely,

Content removed on data protection grounds

9.6.2 6b) Pilot additional questions

Clinician's questionnaire

1) Is the participant information sheet easy to understand?

Yes/No

If no, what needs to be improved?

2) Is the questionnaire easy to follow?

Yes/No

If no, what needs to be improved?

3) Are all the questions clear?

Yes/No

If no, what needs to be improved? Please state, where possible, the specific question you felt was unclear.

4) How long did it take you (in minutes) to complete the questionnaire?

5) Did the questionnaire give you the opportunity to share your experiences?

Yes/No

If no, what needs to be improved?

6) If there are no changes to be made to the questionnaire, following my feedback I am happy that my responses are used within this study.

Yes, I consent to my responses being used.

No, I do not want my responses to be used within the study.

Caregiver's questionnaire

1) Is the participant information sheet easy to understand?

Yes/No

If no, what needs to be improved?

2) Is the questionnaire easy to follow?

Yes/No

If no, what needs to be improved?

3) Are all the questions clear?

Yes/No

If no, what needs to be improved? Please state, where possible, the specific question you felt was unclear.

4) Is the design of the questionnaire accessible?

Yes/No

If no, what needs to be improved?

5) Does the questionnaire use appropriate language for caregivers to understand?

Yes/No

If no, what language do you think needs to be improved?

6) Are there any classifications/descriptors of cerebral palsy you feel are missing?

Yes/No

If yes, please state.

7) Is the process of withdrawal clear?

Yes/No

If no, what needs to be improved?

8) Is there anything else you wish to add?

9.7 Appendix 7

9.7.1 7a) Gatekeepers advert – clinicians

THERAPISTS
Are you a physio or OT working with children with cerebral palsy?
Do you work with them during the transition from primary to secondary school?

If Yes, we want to hear your thoughts and experiences on how you currently provide information to caregivers at this time.

The following questionnaire should take between 10-20 minutes to complete.

Your participation will help us to understand current practice throughout the United Kingdom, highlighting areas of good clinical practice and areas where we can improve to continue to support families and children with a diagnosis of cerebral palsy.

Please click on the link below to complete the questionnaire.

https://coventry.onlinesurveys.ac.uk/infoneeds-therapist-questionnaire

Thank you for your time,
Amy Howells

9.7.2 7b) Gatekeepers advert – caregivers

CAREGIVERS
Do you look after or care for a child with cerebral palsy?
Does your child receive physiotherapy and/or occupational therapy?
Is your child due to move from primary to secondary school or has moved in the last two years?

If yes, then we want to hear your views on what information you have received or what information you would like to receive from physiotherapists and occupational therapists.

We know approaches differ throughout the country, so we would like to find out what is happening in your area, find out what works well and where we need to improve.

The following questionnaire should take between 10 - 20 minutes to complete.

https://coventry.onlinesurveys.ac.uk/infoneeds-caregiver-questionnaire

Thank you for your time,
Amy Howells
Appendix 8

9.8 Appendix 8 - Data Management Plan

1. Overview

1.1 **Postgraduate Researcher:** Amy Howells
1.2 Project title: Physiotherapy and Occupational Therapy Information needs of caregivers of children, living in the United Kingdom with a diagnosis of Cerebral Palsy, during the transition from primary to secondary school education.
1.3 **Project start and end dates:** 01/10/2017 – 01/09/2019
1.4 Project context: Transition from primary to secondary school is a key stage in the development of independence, with children most often than not moving into a new and larger environment with reduced parental access and involvement. The transition of children from primary to secondary school education, within the United Kingdom (UK), is known to be a highly stressful time for families. Caregivers of children with Cerebral Palsy (CP) are no different. Children with CP are known to have a higher level of need in order to successfully manage their condition. Currently, there is no standardised therapy specific information in the UK to support Caregivers to empower their children and assist children with the self-management of their condition. Guidelines, such as NICE (2017), provide a 'gold standard' in regards to suggested information provision however, it is currently unknown how this is translated into clinical practice. Physiotherapists (PTs) and Occupational therapists (OTs) play an important role in providing information to help support children with disabilities to achieve their full functional potential and work towards independent management of their condition. In order to develop standardised information, that can support families during the transition from primary to secondary school education, it is important to understand the current practices throughout the UK and the current information needs of caregivers of children with CP. Therefore, this study aims to explore these current needs and practices on a national scale.

2. Defining your data

2.1 Where does your data come from? 1) Caregivers of children with Cerebral Palsy completing an online questionnaire, circulated through gatekeepers 2) UK registered, Physiotherapists and Occupational Therapists working with children with cerebral palsy during the transition from primary to secondary school.
2.2 What formats are your data in? Collected through Bristol Online Survey
2.3 How often do you get new data? New data will collected during two phases Phase 1 will be collected over approximately a 6 week period through online questionnaire. Phase 2 will be collected over approximately a 6 week period through online questionnaire. New data will not be collected outside of these phases.
2.4 How much data do you generate? 2 pilot questionnaire feedback. Approx. 20 responses from each participant group in phase 1. – 60 in total Approx. 6 responses from each participant group in phase 2 – 18 in total
2.**5 Who owns the data you generate**? Coventry University

3. Looking after your data

3.1 Where do you store your data? Data will be stored within the Bristol Online Survey (BOS) software accessed through the use of Coventry University account. Data removed from this software will be stored on a password encrypted hard-drive. Data will also be stored on Coventry University's One Drive system. Email addresses supplied by participants onto BOS will be downloaded separately from the main data file. Email addresses will be stored separately from the main data file on a password encrypted hard drive.
3.2 How are your data backed up? Data will be backed up on a password encrypted memory stick. Coventry University's One Drive system.
3.3 How do you structure and name your folders and files? Documents will be named with version control and date of file. E.g. Version 1 12 03 18 Structure of files will be categorized by thesis chapter, ie. Proposal, introduction, methodology etc. Within the file – documents will be separated into working document files and previous documents in order to avoid confusion between old and new files.
3.4 How do you manage different versions of your files? Through the use of version control and date of creation of the file listed in the title of the document.
3.5 What additional information is required to understand the data? Not Applicable

4 Archiving your data

4.1 What data should be kept or destroyed after the end of your project? Participant email addresses will be deleted as soon as phase 2 of the study is completed.
4.2 For how long should data be kept after the end of your project? As per Coventry university's research data policy data will be kept as long as it is relevant to the researcher, for a minimum of three years following submission or publication of results.
4.3 Where will the data you keep be archived? Data collected will be archived as per Coventry University's protocol. Data will be transferred onto Coventry University's One Drive system as listed in the above protocol.
4.4 When will data be moved into the archive? Not Applicable
4.5 Who is responsible for moving data to the archive and maintaining them? Researcher as guided by Coventry University data archiving and maintenance systems.

5 Sharing your data

5.1 Who else has a right to see or use this data during the project? Data shared with the supervisory team (Dr Tanya Rihtman, Dr Joanne Opie and Dr Simon Igo) will only be in anonymised form.
5.2 What data should or shouldn't be shared openly and why? All data will be anonymised at point of entry onto the Bristol online survey software. Where participants provide an email address this information will be kept confidential. Any data shared from the study will be anonymised.
5.3 Who should have access to the final dataset and under what conditions? Student Researcher and director of studies will review anonymised data to ensure validity.

5.4 How will you share your final dataset? Not applicable

6 Implementing your plan

6.1 Who is responsible for making sure this plan is followed? Director of Studies and Student researcher
6.2 How often will this plan be reviewed and updated? 6 monthly or where required throughout the project
6.3 What actions have you identified from the rest of this plan? Version controlling agreed with Director Studies. Training on Coventry University One Drive system.
6.4 What policies are relevant to your project? Coventry university data management policy Data protection act
6.5 What further information do you need to carry out these actions? Not Applicable

9.9 Appendix 9 - First-round Qualitative analysis

Barriers to use of patient folder

Topic	
Not implemented/Not done locally	///////////
Uncertainty about responsibility/Not PT role	////
Unaware of 'patient folder'/Don't know what it is	///
Time	/////////
Communication	/
MDT working	/
Caseload capacity	/
Limited resources	/
Engagement	/

Positives of providing information

Topic	
Improvement in transition	/////////
Knowledge/Understanding	//////////////////
Refer back to information	//////
Informed and Supported	/////////
Increased independence/Inclusion/Participation	//////
Continuity of care	//////
Improves outcomes/compliance	//////
Alleviate anxiety	/
Preparation	///////

Barriers (including addition information)

Topic	
Poor communication	//////
Poor information sharing	//
Lack of accountability/responsibility	/
Increased number/variety of staff involved	///////
Availability of staff for training/meetings	//////////
Uncertainty of allocated school/staff	////////
Time	///////////
Lack of awareness/understanding	////
Lack of resources/funding	/////////
Communication difficulties with carers (language/understanding/acceptance)	/////
Volume of information from different sources	//
Capacity of clinicians (caseload)	////
Fear of transition/acceptance with peers	///

Lack of knowledge on individualised information needs	////
Timely and maintaining up to date information	///

Overcome barriers – therapist lead suggestions (including additional information)

Topics	
Training for education staff	///////
Protected time for transition	///////
Lead person/identified responsibility	/////
Improved communication	///
Improved experience/understanding of education	/
Individualised information for education staff (including access to information)	//
Pre-planning	/////////
Pre-visits/Meetings	///////////
Nationally produced standardised information/advice (i.e.apps/leaflets/website) including research	///////////////
Improved MDT approach including plan	/////////
Buddy System/ Support system with other families	//
Caseload management	/
Access to school staff in summer holidays	//